Strategies to Avoid Advanced Dementia

Hemlock Society of San Diego
San Diego Scottish Rite Event Center
November 18, 2018

Thaddeus Mason Pope, JD, PhD

Death is **not** always bad

Life is **not** always good

For many, the alternative to death is **worse**

Goal is **not** to avoid death

Impossible

Goal

Avoid **bad** death

Avoid **2** risks

Dying too **fast**

Dying too **slow**

Default = aggressive

Dying too **slow**

Avoid

advanced dementia

Tricky

No obvious solution

Traditional ADs address post-1960s technology

Ventilator
Dialysis
CPR
Antibiotics
Feed tube

BUT

With dementia, often nothing to “turn off”

2

Types of paths

Act **now** with capacity

Prepare AD for **later**

Now

EOLOA

Most VISIBLE exit option

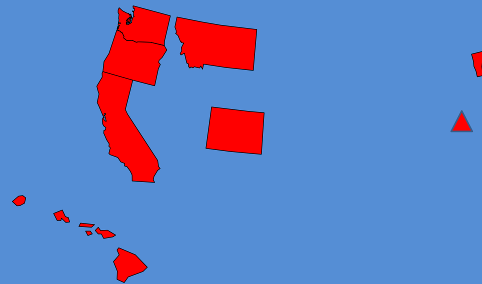
Medical aid in dying

Ask & receive prescription **drug**

Self-administer

To hasten death

MAID legal in **8** US states



BUT

Cannot satisfy 2 conditions at same time

1

Terminal illness

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

2

Decision making capacity

with dementia

Capacity → not terminal

Terminal → no capacity

Cannot satisfy eligibility conditions

May change someday

Dec. 2018

But today

EOLOA **not** helpful for dementia

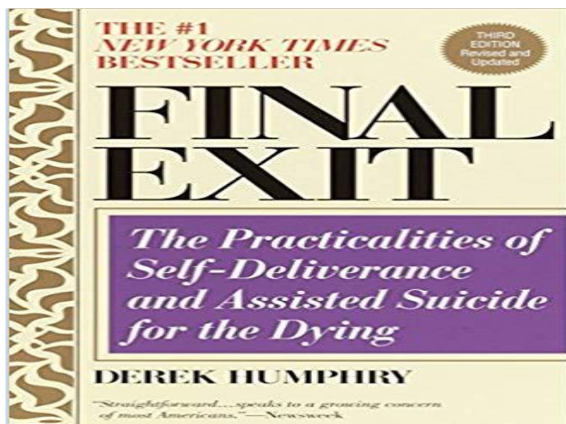
Focus on

Other exit options

2

Act **now** with capacity

Inert gas



Patient must do it **herself**

Get 100% helium

Assemble apparatus

Unique

Most exit options with **clinicians**

Inert gas **non**-medical option

VSED

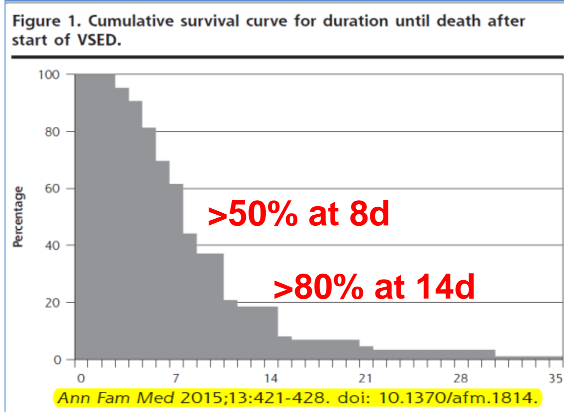
Voluntarily **S**topping **E**ating & **D**rinking

3

Physiologically **able** to take food & fluid by mouth

Voluntary, **deliberate** decision to stop

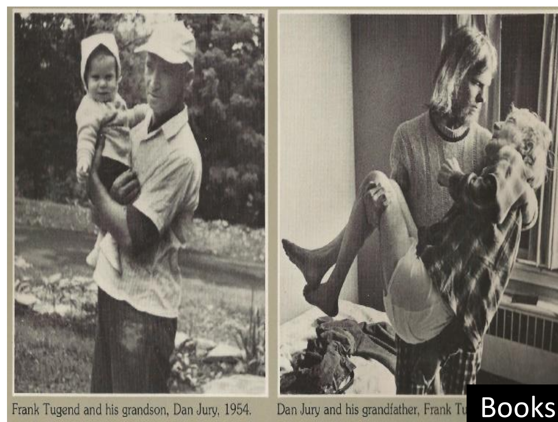
Intent: death from dehydration

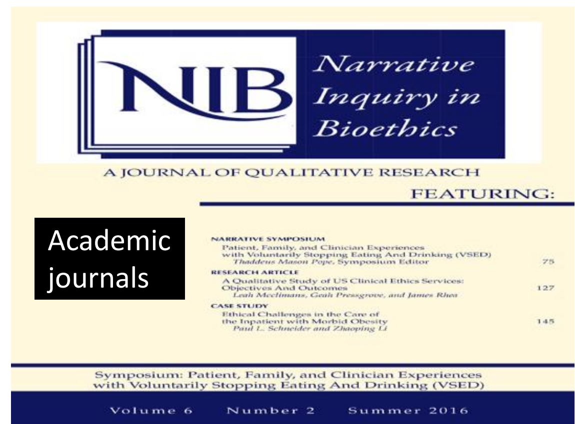


Peaceful

Comfortable

1st person narratives





NIB
Narrative Inquiry in Bioethics
A JOURNAL OF QUALITATIVE RESEARCH

FEATURING:

NARRATIVE SYMPOSIUM
Patient, Family, and Clinician Experiences with Voluntarily Stopping Eating And Drinking (VSED) — 75
Thaddeus Mason Pope, Symposium Editor

RESEARCH ARTICLE
A Qualitative Study of US Clinical Ethics Services: Objectives And Outcomes — 127
Leah Mcclimans, Geah Pressgrove, and James Rhea

CASE STUDY
Ethical Challenges in the Care of the Inpatient with Morbid Obesity — 145
Paul L. Schneider and Zhaoping Li

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

Volume 6 Number 2 Summer 2016

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”

Preferred

by many

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

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

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/s10354-018-0629-z

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
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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

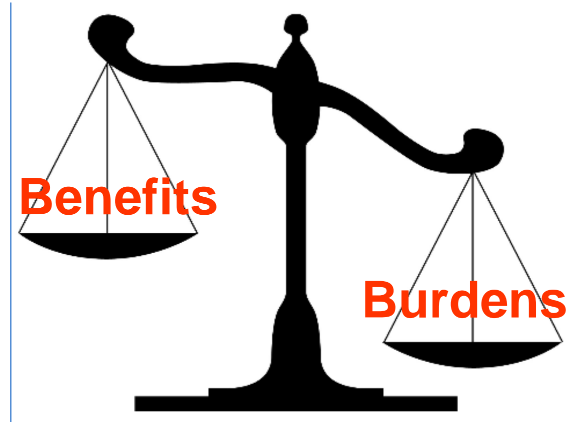
COLLÈGE DES MÉDECINS DU QUÉBEC

Evidence based EOL exit option

Why do it

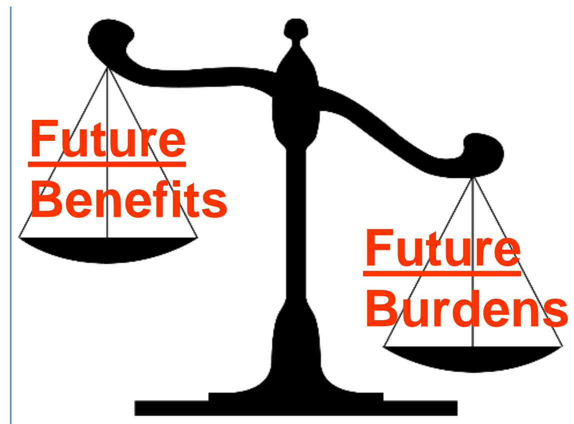
Cancer

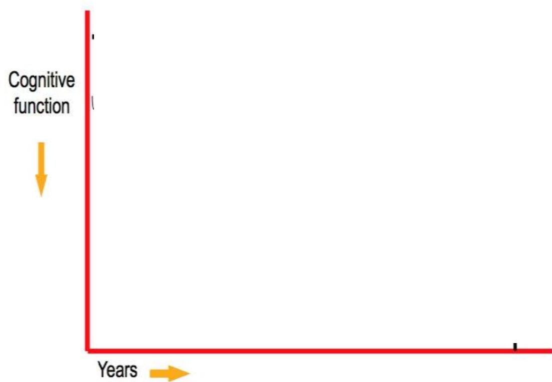
ALS

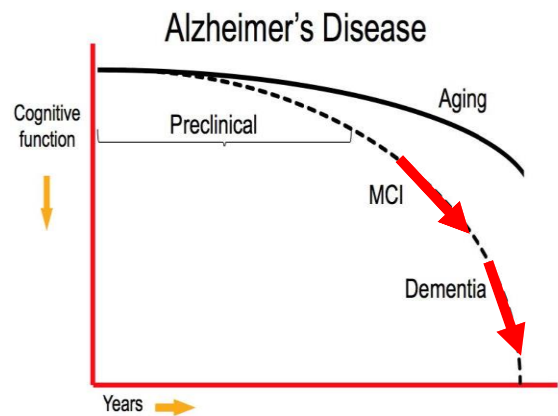


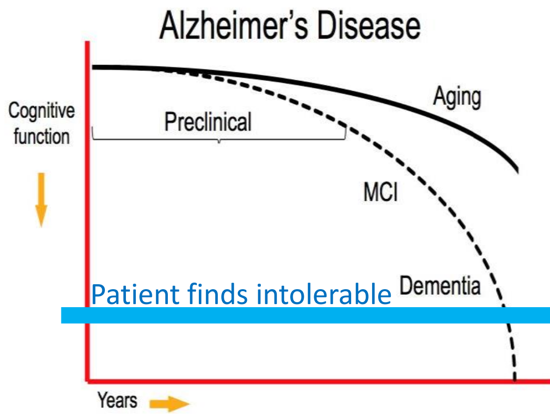
Dementia

Progressive illness





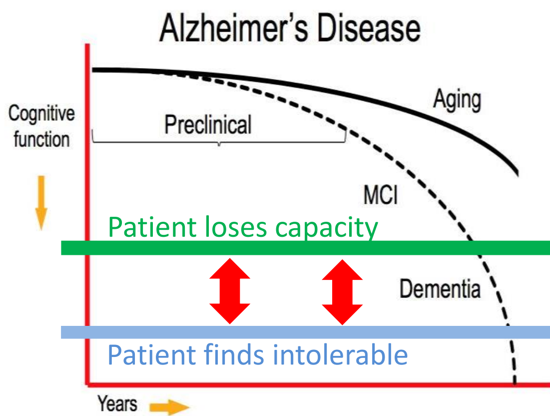


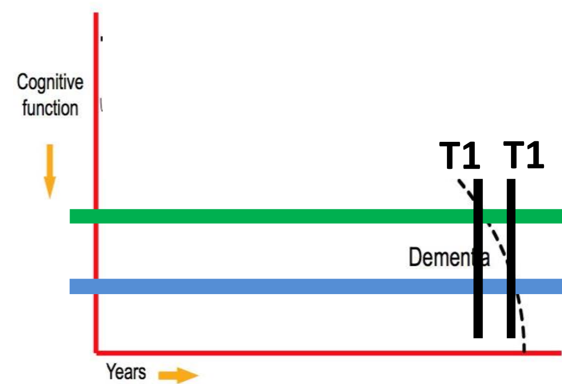


What's that **line**?

Different

for each of us





Hasten death **before** lose capacity

Life **not** now intolerable

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

BUT

Too soon

Hasten death **while** life still worthwhile

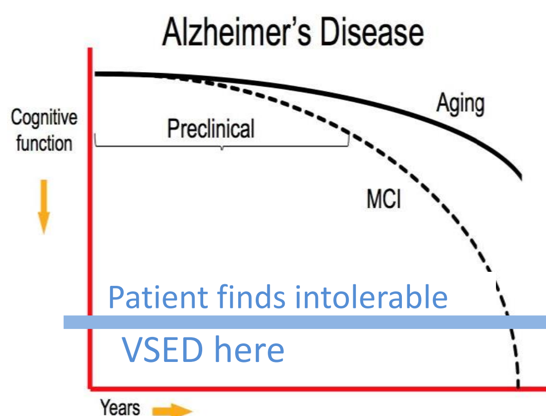
Premature dying

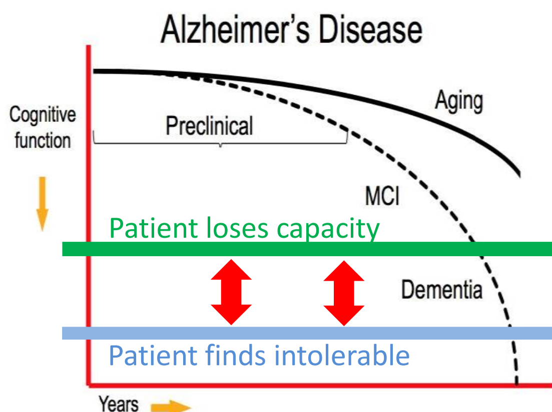
alternative

Advance directive for VSED later

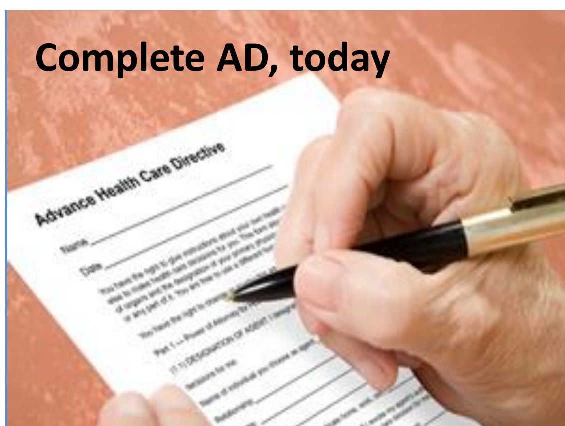
Advantage

Death not hastened **until** point you find life intolerable





What is "advance VSED"



Direct VSED in **future**

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

You **lack** capacity at that time

That is "advance VSED"

Key Question

Can you put VSED instructions in a CA AD?

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

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

12 Tips for VSED Directives

1

Complete advance directive

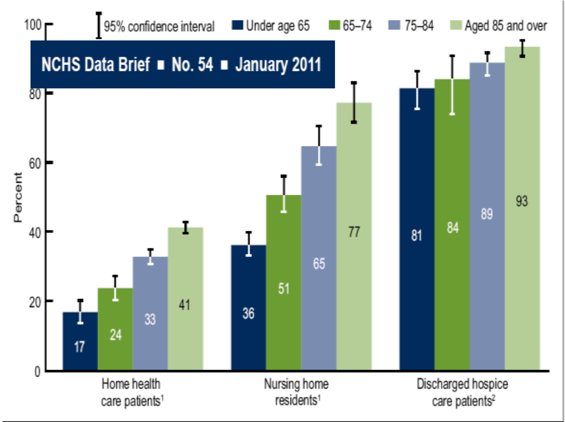
37%

Systematic review of 150 studies (800,000 people 2011 to 2016 Health Aff 2017 36(7):1244

70%

Older Americans

Even higher



Higher still

99497

99498

3 in 10

older Americans do **not**

Even if completed

Not yet done

2

Pick the **right** agent

Best person to act on your behalf is someone **you** know and trust

3

Pick an **alternate** agent

Who can be your agent if your primary agent is **not available**

4

Identify family who should **not** participate

Avoid potential conflict

Clarify not only who **has** authority to speak for you

But also who does **not**

5

Talk to your agent

Not enough to just “designate” your agent

Does your agent **understand** your goals

Does your agent

agree

to honor them

Is your agent a good **advocate** if family or providers disagree

6

Have your agent review **role** of agent

Making Medical Decisions for Someone Else: A How-To Guide

The American Bar Association Commission on Law and Aging

How to Choose a Health Care Proxy

&

How to Be a Health Care Proxy

Institute for Healthcare Improvement

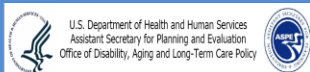
the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

7

Make it findable

76% of physicians whose patients **have** ADs do not know they **exist**



Completed

≠

Have

Not enough to "write it down"

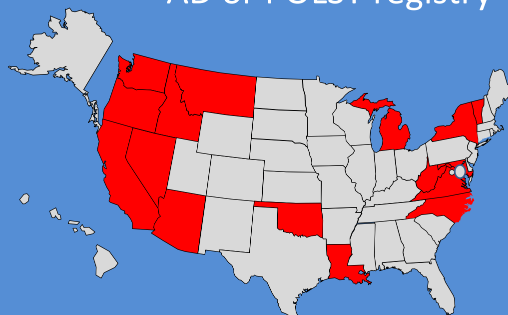
Must be **available**

Only **1/3** advance directives used

Make & distribute copies

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

AD or POLST registry



8

Update AD

ACP is **not** a one-time thing

Reassess Update

Six D's

You reach a new **DECADE** in your age

You experience **DEATH** of a loved one

You experience a **DIVORCE**

You receive **DIAGNOSIS** of a significant health condition

You experience significant **DECLINE** in your functional condition

You change your **DOMICILE** or someone moves in with you

9

Add POLST

Supplement your AD with a POLST

ADs are **not** immediately actionable

e.g. EMS **cannot** follow

Physicians must "translate" ADs to **orders**

POLST

already are medical orders

Immediately actionable

POLST is **not** for everyone

Serious illness and frailty

not be surprised if patient died within the **next year**

10

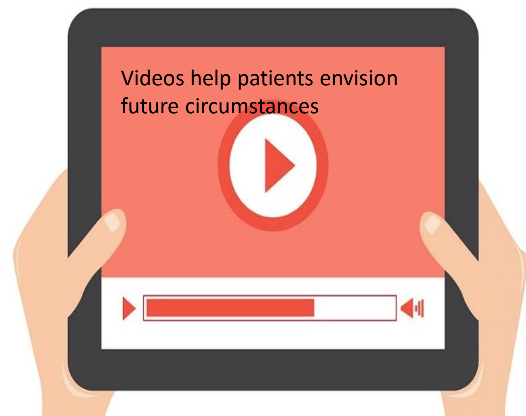
Understand your options

Before recording your preferences, make sure they are **informed**

What exactly is advanced dementia?

Patient decision aids

Improved knowledge



Adv. dementia comfort care

Verbal	**Video**
50%	89%

Deep 2010

"I **know** what I am talking about"

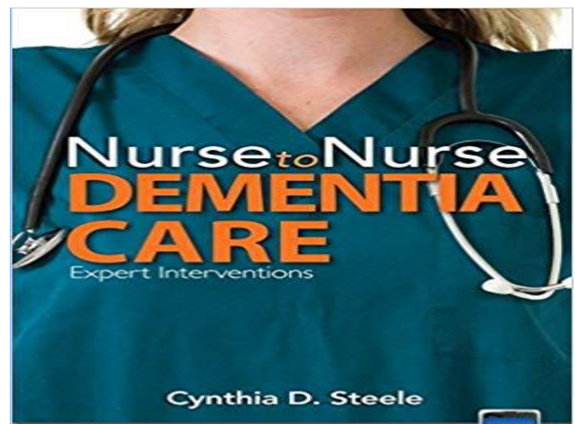
11

Advance VSED

Be clear on the "**what**"

2 recent cases

Case 1



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

I, *Margaret A. Bentley* of *Mission B.C.* 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, *I 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.
C. NO MECHANICAL RESPIRATION WHEN I AM NO LONGER ABLE TO SUSTAIN MY OWN BREATHING.
D. NO SURGERY.
E. OTHER *In the event that mental deterioration is such that I am unable to recognize the members of my family, I ask that I be euthanized.*

I HEREBY DESIGNATE *My husband John L. Bentley* OF *Mission, 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. SHOULD *John Bentley* BE UNABLE TO CARRY OUT MY WISHES, I HEREBY APPOINT *Kathy Kittles* OF *Mission, B.C.* AS AN ALTERNATE PROXY.

WITNESS: *Judy Clifford* SIGNED *M A Bentley*
WITNESS: *R J Clifford* DATE: *Nov. 24/91*

KATHERINE HAMMOND AUG 4, 2013
JOHN BENTLEY AUG. 4, 2013

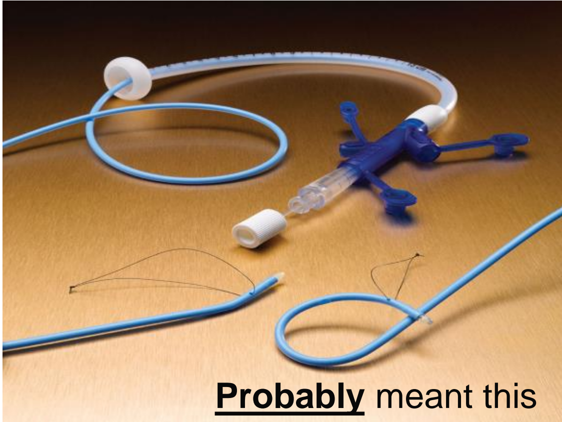
DIRECT THAT I BE ALLOWED TO DIE AND NOT BE KEPT ALIVE BY ARTIFICIAL MEANS OR "HEROIC MEASURES".

B. NO NOURISHMENT OR LIQUIDS.

Family loses

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

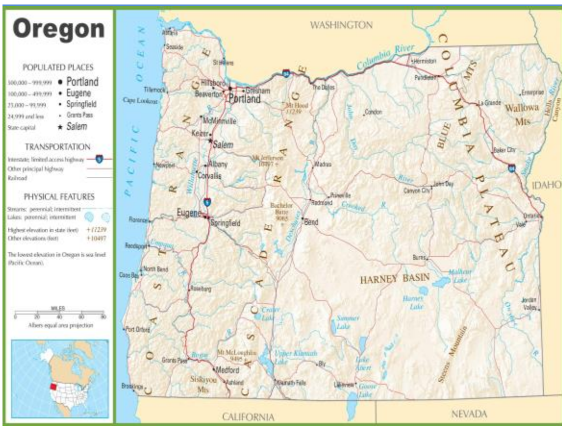
B. NO NOURISHMENT OR LIQUIDS.



Take home lesson

If you mean hand feeding, say “hand feeding”

Case 2



PART 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:

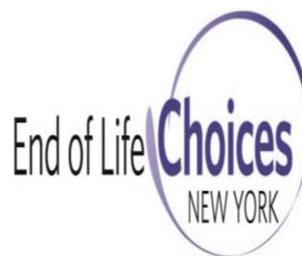
a. I Choose NOT To Prolong Life. If I initial this line, I do **not** want my life to be prolonged and I do **not** want life-sustaining treatment to be provided or continued if **any** of the following conditions apply:

Take home lesson

If you mean hand feeding, **say** "hand feeding"

Tool

MY INSTRUCTIONS FOR ORAL FEEDING AND DRINKING



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

"If I am suffering from advanced dementia . . .
I do NOT want to be fed by hand"

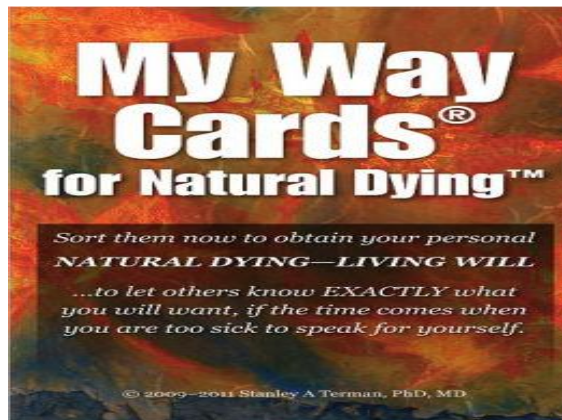
No hand feeding **even if** "appear to cooperate in being fed by opening my mouth"

Be clear on the "what"

12

Be clear on the "**when**"

Tool



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.

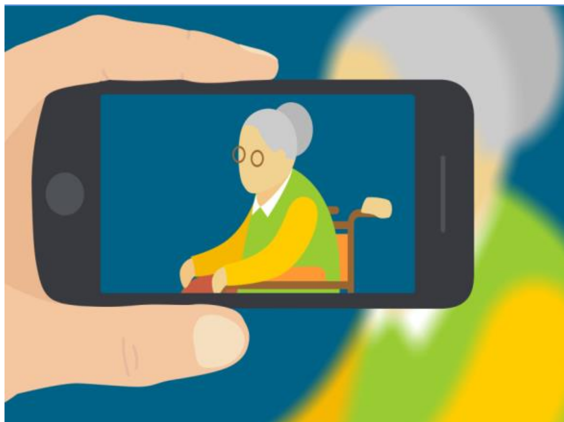
I may yell insulting words or take off my clothes in front of strangers.

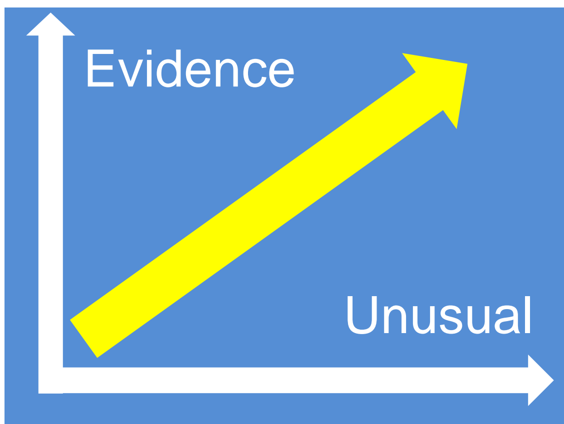
[4.6]

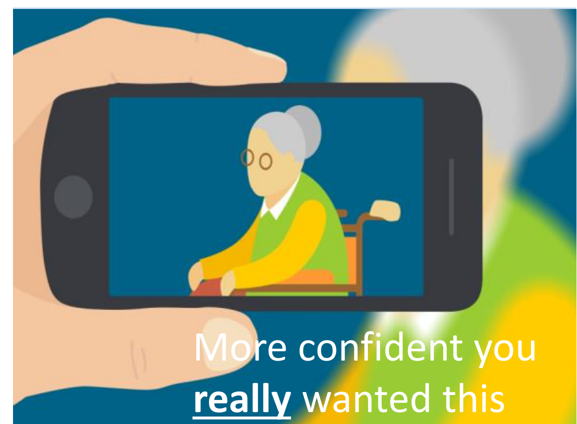
I cannot remember the important events of my life.
If reminded, I don't know why they are important. [1.2]

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]







Your questions

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Materials from the cases discussed in this presentation are available at

http://thaddeuspope.com

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

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Voluntarily Stopping Eating and Drinking, 6(2) NARRATIVE INQUIRY IN BIOETHICS 75-126 (2016) (symposium editor).

Prospective Autonomy and Dementia: Ulysses Contracts for VSED, 12(3) JOURNAL OF BIOETHICAL INQUIRY 389-394 (2015).

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Whether, When and How to Honor Advance VSED Requests for End-Stage Dementia Patients, 19(1) AMERICAN JOURNAL OF BIOETHICS (forthcoming 2019).

Voluntarily Stopping Eating and Drinking Is Legal—and Ethical—for Terminally Ill Patients Looking to Hasten Death, ASCO POST (June 25, 2018).

Voluntarily Stopping Eating and Drinking: Clinical, Psychiatric, Ethical and Legal Aspects, 178 JAMA INTERNAL MEDICINE 123-127 (2018) (with Timothy Quill, Linda Ganzini, Bob Truog).

Voluntarily Stopping Eating and Drinking (VSED) to Hasten Death: May Clinicians Legally Support Patients to VSED? 15 BMC MEDICINE 187 (Oct. 2017).

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