Strategies to Avoid Advanced Dementia
Hemlock Society of San Diego
San Diego Scottish Rite Event Center
November 18, 2018
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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
Medical aid in dying

Most VISIBLE exit option

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 with dementia
Capacity → not terminal

Terminal → no capacity

Cannot satisfy eligibility conditions

May change someday
But today

EOLOA not helpful for dementia

Focus on Other exit options

Act now with capacity

2 Inert gas
Patient must do it herself

Get 100% helium
Assemble apparatus

Unique

Exit Guide Information Request
www.finalexitnetwork.org
<table>
<thead>
<tr>
<th>Most exit options with clinicians</th>
<th>Inert gas non-medical option</th>
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<tbody>
<tr>
<td>VSED Voluntarily Stopping Eating &amp; Drinking</td>
<td>Physiologically able to take food &amp; fluid by mouth</td>
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</table>
Voluntary, deliberate decision to stop

**Intent:** death from dehydration

![Cumulative survival curve](image)

- >50% at 8d
- >80% at 14d

1st person narratives

*Peaceful Comfortable*
Films - Dying Wish

Phyllis Schacter
TED talks

Medical journals

Tomorrow Never Knows

Phyllis Schacter
TED talks

Medical journals

The New England Journal of Medicine

SPECIAL ARTICLE

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

>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
Position Statement

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

Evidence based EOL exit option

Why do it
Cancer

ALS

Dementia

Progressive illness

Burdens

Benefits

Future

Benefits

Future

Burdens

Alzheimer’s Disease

Cognitive function

Years

Cognitive function

Years

Preclinical

Aging

MCI

Dementia
Patient finds intolerable

What's that line?

Different for each of us

Patient lacks capacity at this time

Patient loses capacity

Patient finds intolerable

Patient finds intolerable
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

Patient finds intolerable VSED here
What is “advance VSED”

Complete AD, today

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
3 in 10 older Americans do not

Even if completed

Not yet done

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

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?

Have your agent review role of agent.

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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

Created by the Conversation Project and the Institute for Healthcare Improvement
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

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

Add POLST

Supplement your AD with a POLST

ADs are not immediately actionable

e.g. EMS cannot follow
Physicians must “translate” ADs to 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
Videos help patients envision future circumstances

**Improved knowledge**

Adv. dementia comfort care

<table>
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<tr>
<th>Verbal</th>
<th>Video</th>
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<tbody>
<tr>
<td>50%</td>
<td>89%</td>
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“I know what I am talking about”

Deep 2010

**Advance VSED**
Be clear on the “what”

2 recent cases

Case 1

Margot Bentley
Facility refuses to honor

Family loses
Probably meant this

Take home lesson

If you mean hand feeding, say “hand feeding”

Case 2

Nora Harris
Take home lesson

If you mean hand feeding, say “hand feeding”
“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]

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

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

Advance VSED is new

Evidence

Unusual

More confident you really wanted this
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 Is Legal—and Ethical—for Terminally Ill Patients Looking to Hasten Death, ASCO POST (June 25, 2018).

