Healthcare Decision Making when the Patient Lacks Capacity

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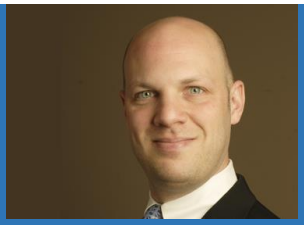
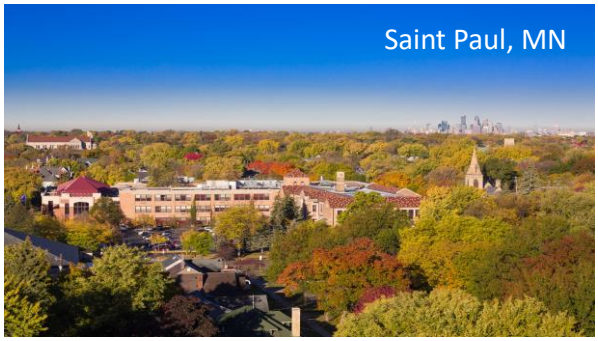
Who is the speaker?



Director, Health Law Institute
Mitchell Hamline School of Law



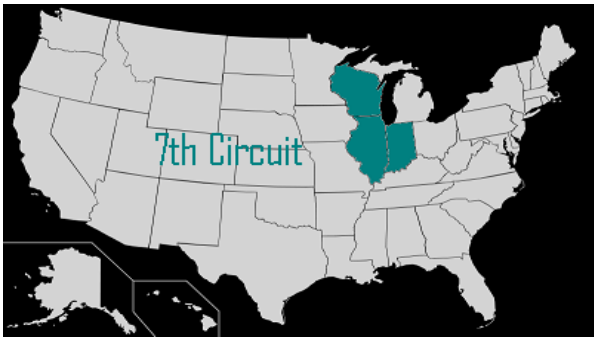
2012 - present

Before that:


Pittsburgh, PA


Georgetown
bioethics


Georgetown Law


7th Circuit


Los Angeles


THE UNIVERSITY OF
MEMPHIS.

I am a **law** professor.

But I often speak and write directly to **clinicians**

The NEW ENGLAND JOURNAL of MEDICINE

JAMA®
The Journal of the American Medical Association

ATS

AMERICAN COLLEGE OF CHEST PHYSICIANS®

Introduction

Try talk to **you**
- to ascertain
what **you** want

If cannot

Try to
identify you

Try contact your
family, so they can
guide treatment

If cannot

Use **fair process** to determine treatment

How well does law & policy measure up?

Roadmap

3 parts

1

Decision making capacity

2

Advance directives

3

Other ways to make healthcare decisions when patient **lacks** capacity

Separate (part 2) video

Capacity

What is "capacity"

3

Able to **understand** significant benefits, risks and alternatives to proposed health care

Able to **make** a decision

Able to **communicate** a decision

2 case examples

Lane v. Candura (Mass. 1978)

Doc thinks stupid decision

But . . . she **understands** the diagnosis & consequences

So, she **has** capacity

DHS v. Northern (Tenn. 1978)

Does **not** appreciate her condition

Believes her feet are black "because of soot or dirt."

That's the **definition**

How to implement

When/How to Assess

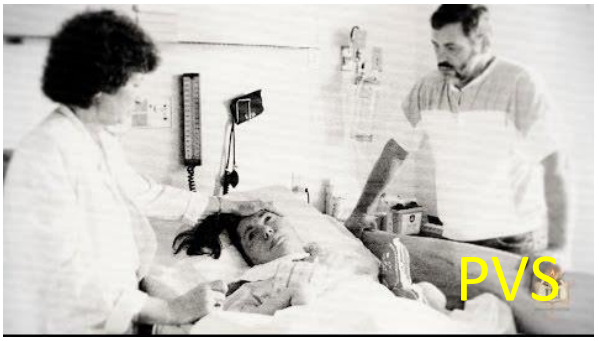
All patients **presumed** to have capacity

Clinicians must **rebut** the presumption

No need to **prove** capacity

Must prove **in**capacity

Sometimes obvious



Often unclear

Assess capacity **carefully**

Not all or nothing

Patient might have capacity to make **some** decisions but not **others**

Patient may lack capacity for **complex** decisions

Still have capacity for **simpler** decisions

Examples

Still have capacity to **appoint** surrogate

May **fluctuate** over time

Patient may have capacity to make decisions in **morning** but not afternoon

AGS Geriatrics Healthcare Professionals

Leading Change. Improving Care for Older Adults.

POSITION STATEMENT

Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

AGS Ethics Committee

POSITION 1

Except in cases of obvious and complete incapacity, an attempt should always be made to ascertain the patient's ability to participate in the decision-making process.

Even if really lacks capacity

Restore capacity if possible

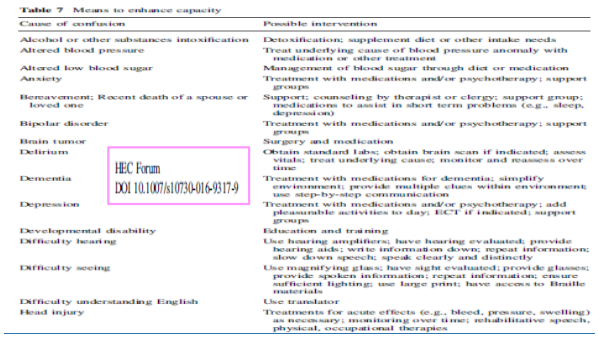


Table 7 Means to enhance capacity

Cause of confusion	Possible intervention
Alcohol or other substances intoxification	Detoxification; supplement diet or other intake needs
Altered blood pressure	Treat underlying cause of blood pressure anomaly with medication or other treatment
Altered low blood sugar	Management of blood sugar through diet or medication
Anxiety	Treatment with medications and/or psychotherapy; support groups
Bereavement; Recent death of a spouse or loved one	Support; counseling by therapist or clergy; support group; medications to assist in short term problems (e.g., sleep, depression)
Bipolar disorder	Treatment with medications and/or psychotherapy; support groups
Brain tumor	Surgery and medication
Delirium	Obtain standard labs; obtain brain scan if indicated; assess vitals; treat underlying cause; monitor and reassess over time
Dementia	Treatment with medications for dementia; simplify environment; provide multiple clues within environment; use step-by-step communication
Depression	Treatment with medications and/or psychotherapy; add pleasurable activities to day; ECT if indicated; support groups
Developmental disability	Education and training
Difficulty hearing	Use hearing amplifiers; have hearing evaluated; provide hearing aids; write information down; repeat information; slow down speech; speak clearly and distinctly
Difficulty seeing	Use magnifying glass; have sight evaluated; provide glasses; provide spoken information; repeat information; ensure sufficient lighting; use large print; have access to Braille materials
Difficulty understanding English	Use translator
Head injury	Treatments for acute effects (e.g., bleed, pressure, swelling) as necessary; monitoring over time; rehabilitative speech, physical, occupational therapies

HEC Forum
DOI 10.1007/s10730-016-9317-9

Bottom line takeaway

Patient has capacity to make decision at hand

Patient decides **herself**

Patients often **lack** capacity

3

Not **yet** acquired (minors)

Never had (mental disability)

Had but **lost** (dementia…)

Most common

Adults **once had** but **later lost** capacity

Can no longer make **own** decisions

Who makes them?

Mechanisms

2 preferred

Advance directive

Agent / DPAHC

2 other

Default surrogate

Guardianship

Promises

Pitfalls

Advance directive

2 parts to AD

Instruct

Appoint

Instruct

FKA
"living will"

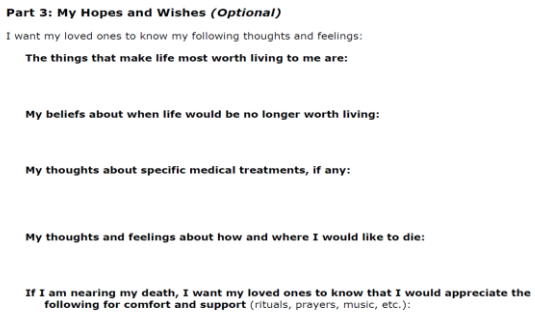
Record treatment
You want
You do not want

Lots of paper
forms, e-forms
& apps

Some are more
treatment
focused

For each of the situations at right, check the boxes that indicate your wishes regarding treatment.	**Situation A** If I am in a coma or persistent vegetative state and have no known hope of recovering awareness or higher mental functions:			**Situation B** If I am in a coma and have a small but uncertain chance of regaining awareness and higher mental functioning:			**Situation C** If I am aware but have brain damage that makes me unable to recognize people, to speak meaningfully, or to live independently, and I have a terminal illness:		
	I want	I do not want	I want a trial; if no clear improvement, stop treatment.	I want	I do not want	I want a trial; if no clear improvement, stop treatment.	I want	I do not want	I want a trial; if no clear improvement, stop treatment.
1. Cardiopulmonary resuscitation. The use of pressure on the chest, drugs, electric shocks, and artificial breathing to revive me if my heart stops.			■			■			■
2. Mechanical respiration. Breathing by machine, through a tube in the throat.									
3. Artificial feeding. Giving food and water through a tube inserted either in a vein, down the nose, or through a hole in the stomach.									

Others are more
goal focused



Part 3: My Hopes and Wishes *(Optional)*

I want my loved ones to know my following thoughts and feelings:

The things that make life most worth living to me are:

My beliefs about when life would be no longer worth living:

My thoughts about specific medical treatments, if any:

My thoughts and feelings about how and where I would like to die:

If I am nearing my death, I want my loved ones to know that I would appreciate the following for comfort and support (rituals, prayers, music, etc.):

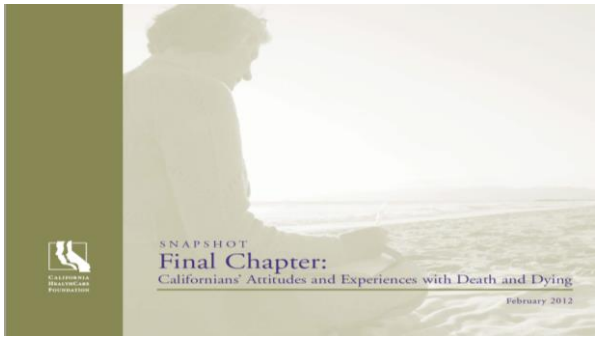
Advantage

Hear from patient **herself**

Best DM for you is **you**

Obstacle 1

Not 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:

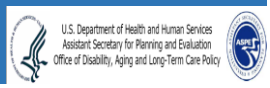
15%

Higher among older & sicker but variable

Obstacle 2

Not found

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



Fail to make & distribute copies

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

Complete ≠ Have

Obstacle 3

Even if completed & available

Not clear

if ___, then ___

If

"Reasonable expectation of recovery"

75%
51%
25%
10%

?

Then

"No ventilator"

Ever

Even if temporary

Vague

Ambiguous

Limits

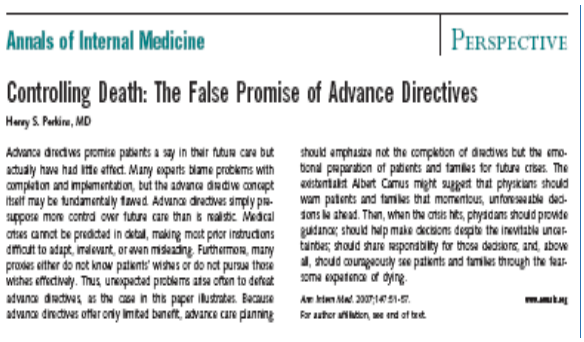
Enough

THE FAILURE OF THE LIVING WILL

by ANGELA FAGERLIN AND CARL E. SCHNEIDER

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

HASTINGS CENTER REPORT March–April 2004



Annals of Internal Medicine | PERSPECTIVE

Controlling Death: The False Promise of Advance Directives

Henry S. Perkins, MD

Advance directives promise patients a say in their future care but actually have had little effect. Many experts blame problems with completion and implementation, but the advance directive concept itself may be fundamentally flawed. Advance directives simply presuppose more control over future care than is realistic. Medical crises cannot be predicted in detail, making most prior instructions difficult to adapt, irrelevant, or even misleading. Furthermore, many proxies either do not know patients' wishes or do not pursue those wishes effectively. Thus, unexpected problems arise often to defeat advance directives, as the case in this paper illustrates. Because advance directives offer only limited benefit, advance care planning should emphasize not the completion of directives but the emotional preparation of patients and families for future crises. The existentialist Albert Camus might suggest that physicians should warn patients and families that momentous, unforeseeable decisions lie ahead. Then, when the crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and, above all, should courageously see patients and families through the fearsome experience of dying.

Ann Intern Med. 2007;147:51-57. www.annals.org

For author affiliation, see end of text.

2 parts
to AD

~~Instruct~~
Appoint

"Agent"
"DPAHC"

1st choice –
patient picks
herself

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

Honoring Choices® MINNESOTA

Health Care Directive English

Introduction

I have completed this Health Care Directive with much thought. This document gives my treatment choices and preferences, and/or appoints a Health Care Agent to speak for me if I cannot communicate or make my own health care decisions. My Health Care Agent, if named, is able to make medical decisions for me, including the decision to refuse treatments that I do not want.

NOTE: *This document does not apply to intrusive mental health treatments, defined as electroconvulsive therapy or neuroleptic medications.*

Any advance directive document created before this is no longer legal or valid.

My name: _____

My date of birth: _____

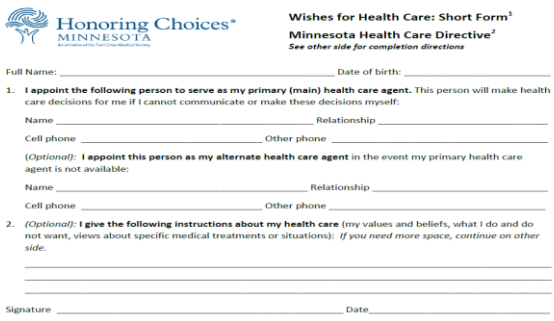
My address: _____

My telephone numbers: (home) _____ (cell) _____

☐ My initials here indicate a professional medical interpreter helped me complete this document.

Part 1: My Health Care Agent

Short form



Honoring Choices® MINNESOTA
A collaborative of the Twin Cities Medical Society

Wishes for Health Care: Short Form[1]
Minnesota Health Care Directive[2]
See other side for completion directions

Full Name: _____ Date of birth: _____

1. **I appoint the following person to serve as my primary (main) health care agent.** This person will make health care decisions for me if I cannot communicate or make these decisions myself:

   Name _____ Relationship _____

   Cell phone _____ Other phone _____

   (*Optional*): **I appoint this person as my alternate health care agent** in the event my primary health care agent is not available:

   Name _____ Relationship _____

   Cell phone _____ Other phone _____

2. *(Optional)*: **I give the following instructions about my health care** (my values and beliefs, what I do and do not want, views about specific medical treatments or situations): *If you need more space, continue on other side.*

   _____

   _____

   _____

Signature _____ Date _____

Notary Public in the State of Minnesota

County of _____ Notary seal

In my presence on _____ (date), _____ (name) acknowledged his or her signature on this document, or acknowledged that he or she authorized the person signing this document to sign on his or her behalf.

Signature of Notary _____

My commission expires _____ (date)

OR Statement of two (2) Witnesses

Witness 1 _____ Witness 2 _____

Date signed: _____ Date signed: _____

Print Name: _____ Print Name: _____

(Witnesses must be 18 years of age or older and cannot be your primary or alternate health care agent. One witness cannot be your health care provider or an employee of your health care provider.)

[1] *A long form is available if you wish to more fully describe your health care wishes.*
[2] *This document will not apply to any intrusive mental health treatments (electroconvulsive therapy or neuroleptic medications).*

Honoring Choices Minnesota is an initiative of the Twin Cities Medical Society. www.metrodoctors.com 612-362-3704 Revised January 2016

BUT

Usually in an advance directive

Not completed

Not found

Still need a SDM

80%

See part 2 "When there is no AD"

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