OREGON HOSPICE ASSOCIATION

DEMENTIA DILEMMA:
The Good, The Bad & The Maybe

Sue D. Porter, MBA, MSB
Founding Executive Director
<table>
<thead>
<tr>
<th>PEACEFUL DEATH</th>
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<tr>
<td>DIGNITY</td>
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<td>COMFORT</td>
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<td>CONTROL</td>
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<td>CHOOSE OWN TERMS</td>
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<td>NO PAIN</td>
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<td>TIMING</td>
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ADVANCE DIRECTIVE

POLST: PHYSICIAN’S ORDER FOR LIFE-SUSTAINING TREATMENT

DNR: DO NOT RESUSCITATE

AID IN DYING ... or not?
WHO DECIDES

AUTONOMY — Ability To Make Own Decision?

SELF-DETERMINATION — Personal Empowerment?

PERSONAL BELIEFS — Patient’s Beliefs and Goals?

BENEFITS vs. BURDENS — Is there a burden?
DWD REQUIREMENTS

TERMINAL ILLNESS ... 6 MONTH PROGNOSIS  X

AN AUTONOMOUS REQUEST ... NO COERCION   X

MENTAL AND PHYSICAL CAPACITY    X
NON-QUALIFIERS

FATAL DISEASE: MORE THAN 6 MONTH PROGNOSIS

CHRONIC, DEGENERATIVE OR DEBILITATIVE DISEASE

TRAUMA RELATED DISABILITIES

DEMENTIA
DEMENTIA: COMPLICATED ISSUE

- Medical
- Legal
- Bioethical
- Religious
- Personal
- Familial
- Societal
- Financial
EUTHANASIA or PHYSICIAN-AID-IN-DYING

EUTHANASIA: Physician makes you die (injection)
Against the law in the U.S.

PAD: Must self-administer the medication
Must make autonomous decision - Dementia?
PRINCIPLES OF MEDICAL ETHICS

BEAUCHAMP and CHILDRESS

• Autonomy - The right to make your own decision
• Beneficence - Act with best interest of person in mind
• Maleficence - Act without malice
• Justice - Fairness and equality among individuals
MENTAL CAPACITY

“SUFFICIENT UNDERSTANDING AND MEMORY TO COMPREHEND IN A GENERAL WAY THE SITUATION IN WHICH ONE FINDS ONESELF AND THE NATURE, PURPOSE, AND CONSEQUENCE OF ANY ACT OR TRANSACTION INTO WHICH ONE PROPOSES TO ENTER.”

WWW.MIRIAM-WEBSTER.COM
DEFINING DEMENTIA

INABILITY TO:

• Recall long-term memories
• Understand ideas & concepts
• Respond to requests
• Use language correctly

• Read or write
• Recognize family or friends
• Remember time or location
• Distinguish between objects
HEALTH CARE PROXIES

Allows control to someone else over health care decisions

Gives direction to the medical community

Reduces conflict between caregivers

Assumes “substituted judgment” ... best interest
HOW CREDIBLE?

ASSUME RIGHT DECISION FOR FUTURE TREATMENT?

• “Then” person vs. the “Now” person
• Can we fully grasp a future situation?
• Could be happy now; change values & preferences
CRITICAL VS. EXPERIENTIAL INTERESTS

CRITICAL INTEREST

“Precedent Autonomy”
Authority of the Health Care Proxy

EXPERIENTIAL INTEREST

“Contemporary Competence”? Considers the person’s present state of being
CONTEMPORARY COMPETENCE?

**PRO**
- Person is suffering irreversibly
- Trust in their Health Care Proxy
- Previous confidence in doctor
- Financial benefactor is long term care

**CON**
- Person currently appears happy
- Inability to communicate clearly
- Inability to understand
- Source of request

EOLCOR | End of Life Choices
OREGON
ARGUMENTS AGAINST

• Timing of dementia and voluntary euthanasia
• Drugs can slow the changes of detrimental brain changes
• By the time diagnosed, could be too late to understand
• Burdens vs. compromise ...“bargaining down”
• Margo
DUTCH CRITERIA - DUE CARE

UNBEARABLE AND IRREVERSIBLE CONDITION

- Request is voluntary and well considered
- Unbearable suffering, without prospect of improvement
- Patient knows the situation and prospects
- No reasonable alternatives to relieve suffering
- Two physicians must agree
- Method used must be done with due medical care and attention
ADVANCE EUTHANASIA DIRECTIVE

AED FOR DEMENTIA - 2002

PRINCIPLES OF DUE CARE MUST BE ADHERED TO

IS THAT POSSIBLE?

INTERPRETATION OF WISHES

POTENTIAL TO ADAPT
HOW TO ASSESS?

• Autonomy ... ability to communicate?
• Should this be a function of psychiatrists?
• How to assess someone who can’t communicate?
• Vulnerable population
• Whose request is this?
• Conflict of interest?
ADVANCE EUTHANASIA DIRECTIVE

**PRO**
- Reiterate in early dementia
- Avoid prolonged suffering
- Honor critical interests
- Substitutive judgment
- Fear of losing “self”
- Loss of dignity and control
- Burden to others
- Financial considerations

**CON**
- Prospective adaptation
- Voluntary and well-considered
- Unbearable and irreversible suffering
- Informed about situation and prospects
- Alternatives to relieve suffering
- Patient can’t deliberate or choose
- Previous document decides
- Who is deciding?
PHYSICIANS’ EXPERIENCES

• Current physician doesn’t know the patient
• Physicians can’t communicate with patient meaningfully
• Questions of who is wanting this ... conflict of interest
• Set limits on life-sustaining treatments
• Few have done it, unless there are comorbidities
DEMENTIA DILEMMA:
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The Bad
The Maybe
RESOURCES


E.E. Bolt et al, *Can Physicians Conceive of Performing Euthanasia in case of ... Dementia...?* JMed Ethics, 2015, Vol.41


S. Frankel, *The Dementia Dilemma*, Perspectives in Biology and Medicine, Winter 1999 (42.2)

P. Menzel & B. Steinbock, *Advance Directives, Dementia and Physician Assisted Death*, Revising the Common Rule, Summer 2013

M.D. Mezey et al, *Advance Directives, Older Adults with Dementia*, Clinics in Geriatric Medicine, May 2000, Vol. 16, Number 2


THANK YOU