

*Responding to Requests for Hastened Death
in an Environment Where the Practice is Legally Prohibited*

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Potential conflicts of interest

I have no financial conflicts of interest around this topic to disclose.

I have been an advocate for legal access to physician assisted death as a last resort option in the United States for over 30 years.

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Case 1

65 year old African American man

- Married for 30 years with 3 grown children
- Worked in computer aspects of regional water delivery
- Very thoughtful, artistic but not religious or spiritual

ALS diagnosed 2 years ago

- Progressive weakness, now largely bedbound
- Uses assisted ventilation at night; worried about future dyspnea
- Has lost 100 pounds from 230 to 130
- Has been wondering and searching online about his “last resort” options
- Most interested in gaining access to a physician assisted death

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Case 2

85 year old Caucasian woman

- Widowed mother of four
- Retired teacher
- Lived alone in her own condo
- Feared being a burden to her children

Early Alzheimer Disease diagnosed 18 months earlier

- Stopped driving and doing her own banking
- Still able to maintain herself in her condo with assistance
- Adamantly wanted to die in her own home
- Wanted to explore her options for dying "*before it was too late*"

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Ensuring Access and Adequacy of Fundamental Healthcare

Traditional medical care

- *State of the science disease directed treatments*

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- *Pain and symptom management*
- *Assistance with medical decision making*
- *Added patient and family support*
- *Potential assistance with end-of-life decision making*

Hospice care as standard of care for dying patients

- *Hospice as a philosophy of care*
- *Hospice as a medical benefit*

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LIMITATIONS OF PALLIATIVE CARE AND HOSPICE

False reassurance

Exceptions unacknowledged

Uncontrollable physical symptoms

Psychosocial, existential, spiritual suffering

Dependency, side effects

Devaluation of some patient choices

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Some Data from Washington State Motivations for Seeking a Hastened Death

Illness-related experiences

- Feeling weak, tired, uncomfortable (69%)
- Loss of function (66%)
- Pain or unacceptable side effects of pain meds (40%)

Threats to sense of self

- Loss of sense of self (63%)
- Desire for control (60%)
- Long-standing beliefs in favor of hastened death (14%)

Fears about the future

- Fears about future quality of life and dying (60%)
- Negative past experience with dying (49%)
- Fear of being a burden on others (9%)

IT AIN'T PAIN, AND IT AIN'T SIMPLE

(Pearlman / Starks in Physician-Assisted Dying .2004 J Hopkins Press 91-101.

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Palliative Options of Last Resort: Why are they important?

Reassurance for witnesses of bad death

Potential escape when suffering unacceptable

Awareness of potential options important to some patients,
families, and caregivers

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Reassurance about the future

Commitment to be guide and partner

Explore hopes and fears

- *What are you most afraid of?*
- *What might death look like?*

Commitment to face worst case scenario

Freedom to worry about other matters

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Some Data from Oregon

(Tolle S et. Al. J Clin Ethics.2004;15:111-8)

1/6 talk to their families

1/50 talk with their doctor

1/300 deaths by PAD

MOST PEOPLE WANT TO TALK

VERY FEW ULTIMATELY ACT

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Will You Help Me Die, *NOW*?

Full exploration; Why now?

Potential meaning of the request

- Uncontrolled symptoms
- Psychosocial problem
- Spiritual crisis
- Depression, anxiety

Potential uncontrolled, intolerable suffering

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Will You Help Me Die, *NOW*?

Insure palliative care alternative exhausted

Search for the least harmful alternative

Respect for the values of major participants

Patient informed consent

Full participation of immediate family

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Potential Last Resort Options

Accelerating opioids to sedation for pain or dyspnea

Stopping life-sustaining therapy

Voluntarily stopping eating and drinking

Palliative sedation, potentially to unconsciousness

Physician assisted death (aka physician assisted suicide)

Voluntary active euthanasia

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VOLUNTARILY STOPPING EATING AND DRINKING

Key Elements

Result of active patient decision

Patient physically capable of eating and drinking

Requires considerable patient resolve and discipline

Takes one to two weeks

Does not require physician involvement

Symptom management as process unfolds

- *Dry mouth*
- *Delirium*

Probably legal but never been tested

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PALLIATIVE SEDATION, POTENTIALLY TO UNCONSCIOUSNESS

Key Elements

Sedation potentially to unconsciousness, life-supports withheld

Uses benzodiazepines or barbiturates

Process usually takes days to a week

Patient dies of dehydration or complication of sedation

Patient unaware of suffering

Combination of “double effect” and withholding of life-sustaining therapy

Legal option for patients who lose capacity

Utilization varies remarkably between sites and programs

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Options in States where PAD is Legally Prohibited

Organizations supporting more end of life choices

- Compassion and Choices
- End of Life Choices New York
- Death with Dignity National Center
- Final Exit Network (Hemlock Society)
- World Federation of Right to Die Societies

Information: *legal and underground "last resort" options*

Counseling: *for those actively considering one of these options*

Presence: *(sometimes) for those using a "last resort" methods*

Advocacy: *expand and liberalize laws regulating these practices*

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PALLIATIVE OPTIONS OF LAST RESORT

The Need for Safeguards

Protect vulnerable from error, abuse, coercion

Ensure access and adequacy of palliative care

Make sure requestors are aware of the full range of options

Risks cited for PAD are also present for other last resort options

Safeguards must balance

- *Flexibility and accountability*
- *Privacy and oversight*

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PALLIATIVE OPTIONS OF LAST RESORT

Categories of Safeguards

Palliative care accessible and found to be ineffective

Rigorous informed consent

Diagnostic and prognostic clarity

Independent second opinion

Documentation and review

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Advantages of Being Explicit about Last Resort Options

Acknowledges the problem

- Less patient and family fear
- Free energy for other more important tasks

Reinforces the physician imperative to be responsive

- Nonabandonment
- Get help if you need it!

Be clear about what you can and cannot do to help.

- Law tells you about that is legal, not necessarily what is ethical
- Should try to be as responsive as possible, but...
- *Should not violate fundamental personal principles regardless of law*

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Return to Patient with Advanced ALS

Not clinically depressed

- Up until very recently he was actively involved in his work
- Enjoyed being with his wife and family
- Exploration was consistent with longstanding personal values
- Hospice referral to maximize palliative care

Last resort options that might address his situation

- Promise of aggressive sx management when the time comes
- Promise of palliative sedation if needed when the time comes
- Possibility of voluntarily stopping eating and drinking at a time of his choosing
- Possibility of physician assisted death (his very clear preference)
 - Exploring the underground practice

Work in progress...

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Return to Patient with Early Alzheimer Disease

Met every three months with her and her family

- Initially thinking over her options
- Wanted to be sure her children would be okay
- Making sure she was doing this mainly for her and not them
- Risk of acting prematurely vs. risk of waiting too long
- Consultation with her PCP and her neurology consultant

Decided upon a date

- Final meeting to ensure she was still certain about going forward
- Celebratory meal with her family
- Arranged for 24 hour presence with family and professional caregivers
- She remained very disciplined and died peacefully 12 days later in her own bed in her own home surround by her children

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Websites for Right to Die Advocacy Organizations

- Compassion and Choices
<https://www.compassionandchoices.org/>
- End of Life Choices New York
<http://endoflifechoicesny.org/>
- Death with Dignity National Center
<https://www.deathwithdignity.org/>
- Final Exit Network (Hemlock Society)
<http://www.finalexitnetwork.org/>
- World Federation of Right to Die Societies
<http://www.worldrtd.net/>

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