Who Decides How You Will Die?

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How People Want Their Lives to End

Journal of the American Society on Aging, June 2015

1. To be at home with loved ones
2. To have their pain and discomfort managed
3. To have their spiritual needs respected
4. To avoid being a financial or emotional burden on their loved ones.

How do the dying define "Dying Well"

American Journal of Geriatric Psychiatry, April 2016

1. Having control over their own dying process
2. Being free from pain
3. Having emotional and spiritual needs met
4. Having a sense that their lives were complete

Factors that can undermine advance care planning:

1. Healthcare systems whose imperative is to "save" lives
2. People who do not agree with the dying person's values and wishes, and who have the power to override or disregard them
3. Incompetent or inadequate end-of-life care
4. Politics surrounding how and when you are allowed to die.

Elements of an ordeal:

1. Failure of hospice
2. Vaguely-worded criminal law
3. Criminal (in)justice in the U.S.
4. Politics

PA Criminal Code: §2505(b) Aiding Suicide

A person who intentionally aids or solicits another to commit suicide is guilty of a felony of the second degree if his conduct causes such suicide or attempted suicide, and otherwise of a misdemeanor of the second degree

The law recognizes no distinction between mental health crises that cause people to end their lives prematurely vs. the wish of the terminally ill to die in peace and comfort in a way that aligns with their personal values and wishes. The only jurisdictions that make this distinction are those that allow medical aid-in-dying: Oregon, Washington, California, Hawaii, Montana, Colorado, Vermont, and the District of Columbia.

Hospice Care – excerpts from 42 CFR, Ch IV, part 418:

- The hospice must provide hospice care that optimizes patient comfort and dignity.
- Nursing services, physician services, and drugs and biologicals must be made routinely available on a 24-hour basis 7 days a week.
- The hospice must ensure that drugs and biologicals meet each patient's needs.
- Payment is made to the hospice for each day during which the beneficiary is under the care of the hospice, regardless of the quantity or quality of services furnished on a given day.

July 2018 OIG of HHS released a 41-page report:

Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity: An OIG Portfolio.
https://oig.hhs.gov/oei/reports/oei-02-16-00570.pdf

Some highlights from the OIG report:

- Use of hospice care has grown steadily over the past decade; in 2016, Medicare paid $16.7 *billion* for this care.
- OIG found that hospices do not always provide needed services to beneficiaries and sometimes provide poor quality care.
- OIG also found that beneficiaries and their families and caregivers do not receive crucial information to make informed decisions about their care.
- OIG conducted criminal and civil investigations of hospice providers, leading to conviction of individuals, monetary penalties, and civil False Claims Act settlements.
- The current payment system creates incentives for hospices to minimize their services and seek beneficiaries with uncomplicated needs. Within each level of care, Medicare pays hospices for each day a beneficiary is in care *regardless of the quantity or quality of services.*
- Medicare pays for four levels of hospice care:
  Routine home care – reimbursed at $190.55/day
  General inpatient care – reimbursed at $734.94/day
  Continuous home care (during brief periods of crisis) – $964.43/day
  Inpatient respite care - $170.97/day

- All services related to the terminal illness become the *hospice's responsibility*. Yet hospices do not always provide the care beneficiaries need to control pain and manage symptoms.
- Hospice Compare – a website launched by CMS to help beneficiaries choose a hospice – does not include critical information about the quality of care provided by individual hospices, nor information about complaints filed against individual hospices.
- OIG recommended better oversight of hospices, statutory remedies for poor performance, and greater dissemination of information about hospices so beneficiaries and their caregivers can make informed choices.

Questions to ask when interviewing hospices:

- Is staff available 24 hours/day, 7 days/week?
- How do you ensure that patients obtain their desired level of comfort?
- Who will direct the hospice patient care?
- What education is provided for the patient and caregivers?
- Will you ever override a patient's advance directive? Under what circumstances?
- How many patient and caregiver complaints were received in the last year? How were they resolved?
- How many patients and caregivers terminate services? What are the reasons?
- Is the hospice concerned about opiate addiction in their patients? (The CDC specifically exempts the dying and cancer patients from restrictions in opiate prescribing.)

More detailed information available at:
http://palliativedoctors.org/uploads/hospice/09jama.pdf

Advance Care Planning Documents

- Few healthcare systems prioritize ACP, and documents often cannot be located when needed
- Clients need to have hard copies with them or easily accessible
- Don't assume they will be available in electronic health record