END OF LIFE OPTION ACT

Our Aging Nation
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SETTING THE STAGE

- Life expectancy 1900 40 yrs, 2000 80 yrs
- 1900 – infectious diseases caused death
- 2000 – degenerative diseases caused death
- During the last 50+ years, medicine has become increasingly capable of postponing death
- Death moved from the home into the hospital – transitioned from being a natural process to a medical process

SETTING THE STAGE (cont'd)

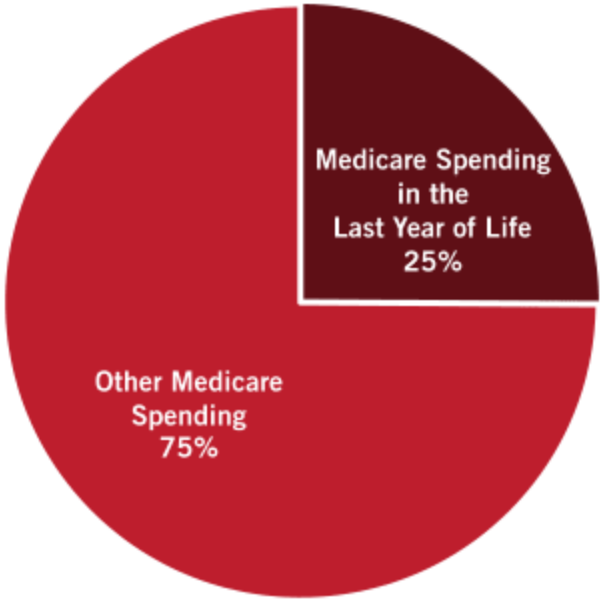
- Nearly half of all Americans die in a hospital
- Nearly 70% die in a hospital, SNF or long-term care facility
- 9 out of 10 want to die at home
- Almost 1/3 see 10 or more physicians in the last 6 months of life
- 20-30% report having an advance directive
- 25% of PCPs knew that their patients had an AD

THE COST OF DYING

- Economic
  - Patients with chronic illness in their last 2 years of life account for about 32% of total Medicare spending
  - Medicare covers 1/3 of the cost of treating cancer in the final year, 78% occurring in the last month
  - Costs about 1/3 less if an EOL discussion

PETER G. PETERSON FOUNDATION

One in four Medicare dollars is spent on people who are in the last year of life



SOURCE: Health Services Research, *Long-Term Trends in Medicare Payments in the Last Year of Life*, April 2010. Compiled by PGPF.
NOTE: Data are from 2006, the most recent available.

THE OTHER COST

- Emotional
  - Suffering for the dying patient
  - What some medical staff view as futile treatment
  - Mental anguish for loved ones making decisions

DYING IN AMERICA

- America: The only country where death is optional
- Dying increasingly involves *choice*
  - Aggressive treatment?
  - Palliative care?
  - Hospice care?
  - Life-ending medication?

LANGUAGE

- Death with Dignity Act – OR and WA
- Patient Choice & Control at End-of-Life Care Act – VT
- End-of-Life Option Act – CA and MT
- Physician-Assisted Death
- Physician-Assisted Suicide
- Aid in Dying

The Oregon Experience

- 480,000 people died between 1998 & 2013
- 752 hastened death (1,173 prescriptions)
- 53% male
- 98% Caucasian
- 46% married
- 72% college educated
- 90% enrolled in hospice
- 98% had insurance
- 95% died at home

Reasons for Using the Law

- Autonomy
- Ability to enjoy life
- Loss of dignity
- Control of bodily functions
- Burden on family, friends, caregivers
- Inadequate pain control or concerns about pain
- Financial implications

2014 Statistics: Oregon

- 155 prescriptions written in 2014
- 94 patients ingested the medication
- 37 did not ingest meds and died of underlying disease
- 24 ingestion status unknown
- 11 patients with earlier prescriptions ingested meds in 2014
- 105 died from ingesting meds (94+11)
- 0.3% of Oregon deaths in 2014

Where We Are Today

- Legal in California as of June 9, 2016
- Sunset Clause (unique to California): The law remains in effect until 1/1/2026 unless another statute is enacted to extend

End-of-Life Option Provisions

- Allows terminally-ill adults to request a prescription for self-administered lethal medication
- Prohibits euthanasia
- Clarifies ending life through this option is *not* suicide or assisted suicide under California statutes

Law Contents

- Terminally ill, competent adult (18+)
- Resident of California
- Medically predicted to die within 6 mos.
- Decision-making capacity
- Physical and mental ability to self-administer the medication
- Request made "solely and directly" by the individual, not on behalf of

- 2 physicians (attending/consulting) affirm diagnosis, competence and decision-making ability
- Physician must discuss feasible alternatives, such as hospice, PC
- Optional referral to psychologist/ psychiatrist if concerned about mental health affecting competency

- Patient makes 2 verbal requests and 1 written request
- 15-day waiting period between verbal requests
- 2 witnesses sign/date written request form
- Witness cannot be involved physician or mental health specialist
- Only one witness can be related by blood, partnership, adoption, etc.
- Patient also signs an attestation form 48 hours prior to ingesting medication

- Not considered suicide, so no benefits lost
- Underlying illness noted as cause of death
- Recommendations from the law:
  - Have another person present
  - Notify next of kin/family
  - Don't take in a public place
  - Participate in a hospice program
  - Keep meds safe until ingestion

Protection for Healthcare Workers

- No civil or criminal liability or neglect for providers acting in good faith, including being present when patient takes the medication
- No censure, discipline, loss of license, privileges, or membership, or other penalties to members of professional organizations for either participating or not participating

Opting Out

- Providers may opt out because they are unable or unwilling to participate
- Can continue to provide other patient services while abstaining from fulfilling the request

Institutional Prohibitions Allowed

- Institutions (organizations) may prohibit employees from participating in the act
- Must provide written notice to the employees and the general public regarding its policy
- Policy allows providers to give all other services

Medication

- Secobarbital (Seconal) most frequently used
- Cost is $3000 to $5000
- Medicare will not cover the medication
- MediCal funds made available to cover the cost
- Most private insurance companies will cover

Points to Consider

- Requires thoughtful debate and discussion
  - Focus on organization mission
  - Focus on patient needs
- Be Prepared
  - Level of organizational involvement
  - Policy creation
  - Staff training

Levels of Involvement

- **Full participation**
  - Medical professionals associated with organization write prescription
  - Staff can be present at time of ingestion and actively support patient and family during the process
- **Partial participation**
  - Medical professionals may serve as consulting physicians
  - Facilitate referral to Compassion & Choices
  - Staff may or may not be present at ingestion, depending on agency policy

Levels of Involvement

- **Limited participation**
  - Refer to appropriate support organization, such as Compassion & Choices
  - Staff not allowed to be present
- **No participation**
  - Refuse to allow staff to discuss option with patient
  - Do not make referral to outside organization
  - Refuse to accept or serve patients

Informed Consent Policy

Once level of involvement is decided:

- **Patient/resident right to accurate information**
- **Patient/resident right to non-judgmental care**
- **Support of patient/resident self-determination**
- **Patient/resident made aware of level of organizational/facility involvement at time of hospice admission**

Staff Opting Out

- Develop policy and process for staff to:
  - Opt out of caring for patients who receive the medication
  - Transition care to different staff
- Train staff on how to have conversations that are patient-centered, not provider-centered
  - Explore the "why" behind the request
  - Assess for unmet needs
  - Maintain non-judgmental body language/words

Staff Training

- Train on your policies
- Be sensitive to differing opinions
- Create open dialogue
- Plan to retrain 2-3 months after implementation

Responding to Requests

- Opportunity for conversation – may be the icebreaker for patient
- Learn about the alternatives
  - Withholding/withdrawal of life-sustaining treatments
  - Hospice & palliative care
  - Voluntary withdrawal of oral intake
  - Palliative sedation for severe intractable symptoms

- Reflect on your personal feelings – discuss with other professionals
- Balance integrity and non-abandonment
  - Be as specific as possible about what you can/cannot do, explain why
  - Search for alternative options that may be acceptable
  - Refer to other clinicians for what you cannot do

Next Steps

- If you haven't yet developed a policy, start policy development discussions ASAP
- Complete policy development ASAP
- Focus on training staff to your policy
  - Can be a bumpy road when policy becomes procedure – lots of emotion, worsened if unclear about policy

Policy Considerations

- What is your level of organizational participation?
- If you own a facility, will you allow patients/residents to take the medication in your facility?
- How will you inform current patients/residents about your policy?
- How will you inform future patients/residents about your policy?

Education Considerations

- How much education will you provide to your staff about eligibility for the Act?
- What is your expectation for how your staff will handle requests from patients/residents, even if just for information?

Staff Support

- What will you put in place to support your staff who struggle with their own feelings regarding the law?
- How will you support staff who engage in conversations with patients/residents about the law, or are supporting family members with conflicting feelings?

New Territory

Know this: Whatever you decide today, count on revisiting it as situations arise.

Keep your agency policy general – should not change much

Create a best practice for your staff that can be "tweaked" as you go along

Resources

- *The Oregon Death with Dignity Act: A Guidebook for Healthcare Professionals*, https://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethics-outreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf
- *Dignity, Death & Dilemmas*, Journal of Pain & Symptom Management, Vol. 47, No. 1, pp. 137-153
- California Information Hotline, http://www.EndofLifeOption.org
- Compassion and Choices, http://www.compassionandchoices.org

Questions?