CALIFORNIA END OF LIFE OPTION ACT

Lael Duncan, MD
Medical Director of Consultation Services
lduncan@CoalitionCCC.org @lduncanmd
Objectives

• Describe the purpose of the End of Life Option Act in California. (EoLOA)
• Demonstrate knowledge of demographics in states where similar legislation is in place
• List requirements for patient eligibility.
• Demonstrate knowledge of the process for implementation
• Describe the ethical considerations underlying actions providers and healthcare workers may choose to take
• Discuss how organizations can address the formation of a policy for responding to patients and families.
End of Life Option Act Resources

• California Medical Association & Ca. Medical Board

• On Call Brief Document 3459 CMA legal staff
  • http://www.cmanet.org/resource-library/detail/?item=the-california-end-of-life-option-act

• Coalition for Compassionate Care
  • http://coalitionccc.org/tools-resources/end-of-life-option-act/

• UC Hastings Consortium Document

End of Life Option Act Task Force
CCCC Perspective

Our goal is to:

• **Assist healthcare professionals with learning how to guide patients in exploring their options for care during a serious illness,**

• **help patients express their informed choices,** and

• **strengthen the healthcare environment where those personal choices will be honored.**
The End of Life Option Act

On October 5, 2015, California became the fifth state in the nation to allow a terminally ill patient to request a drug to end their life, prescribed pursuant to the provisions of the law.

- Oregon – 1998
- Washington - 2008
- Montana – 2009
- Vermont – 2013

The California End of Life Option Act (“EoL OA”) becomes effective June 9, 2016
Acknowledge the road.
In context

Patient Autonomy
Shared decision making
Beneficence vs non-maliciousness
Personal integrity
Professionalism
AB X2-15: The End of Life Option Act

Terminology

• Physician assisted death/dying (PAD)
• Medical aid in dying
• Aid in dying drug
New California End of Life Option Act

New Legislation:
AB X2-15 End of Life Option Act: Gives interested patients a legal right to choose and receive medication to hasten death in setting of terminal illness.

Becomes active June 9, 2016
The legislation covers:

- Patient eligibility
- Actions of the attending physician, consulting physician and mental health specialist
- Actions for healthcare organizations
- Protections and immunities
- Management of medications
Participation and eligibility

• No provider, healthcare worker or organization is required to participate or to refer patients

• Not all providers or patients CAN participate
Patient eligibility

- Adult patient (18 years or more)
- Resident* of California
- Terminal* illness

Terminal = incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, result in death within six (6) months.

- Capacity* to make medical decisions
- Request is fully voluntary and in person
- Can self-administer medication

*Terms defined in the legislation and on forms
Process, Participation

Requires involvement of 2 physicians minimum:

• **Attending Physician**...has primary responsibility for the health care of an individual and treatment of the individual’s terminal disease.

• Chosen by the Patient

• **Consulting Physician**...a physician independent from the attending who is qualified by specialty or experience to make a diagnosis or prognosis regarding a terminal disease.

• **Mental Health Specialist**

If there is any question of a mental disorder, a “mental health specialist” (psychiatrist or licensed psychologist) must determine the individual has *capacity to make medical decisions.*
Process

- 2 oral requests to the Attending >15 days apart
- 1 witnessed written request to the Attending
- Attending and Consulting physician agree on:
  - Diagnosis of a terminal disease
  - Prognosis of 6 months or less of life
  - Capacity to make medical decisions (Mental Health referral if indicated)
- Proper documentation
- Patient properly informed & counseled
- Patient attestation form 48 hours prior to self-administered aid-in-dying drug ingestion
Forms defined by the Act

• Written request
• Attending physician check list & compliance form
• Consulting physician compliance form
• Interpreter’s declaration if used
• Final attestation
• Attending physician follow up form

**Medical Board of CA** provides oversight of forms

**CDPH** will have forms available on the website
Responsibilities of the Attending Physician

- Determine if patient is eligible & qualified
- Assess terminal disease
- Assess capacity for decision making
- Confirm voluntariness of request
- Rule out mental disorder or refer for evaluation
- Rule out coercion or undue influence
- Complete proper documentation
- Counsel the patient
Responsibilities of the Attending Physician continued.

To confirm the patient is making an informed decision.

Discuss the following:
- Diagnosis, prognosis
- Result of ingesting aid-in-dying drug
- Option to obtain drug and not take it
- Feasible alternatives (specified)

Refer to Consulting Physician
Responsibilities of the Attending Physician

Counsel the patient about importance of:

- Having another person present
- Choice of location (not public)
- Notifying next of kin
- Participation in hospice program
- Keeping drugs in safe place
- Option to withdrawal or rescind request—required at time of evaluation and when writing prescription
Discussing alternatives to assisted death

- *Palliative care, comfort care*
- *Pain management*
- *Hospice care*
- Withdrawal or withholding of life sustaining treatments
- *Palliative sedation*
- Voluntary stopping of eating and drinking
Responsibilities of the Consulting Physician

- Examine the patient
- Confirm terminal diagnosis/prognosis
- Confirm capacity for decision-making, acting voluntarily, making informed decision
- Fulfill documentation in record
- *Submit the compliance form to attending MD*
Participation

Participation is voluntary

- Offering advise or counsel about EoLOA is not required if individuals or organizations are opposed by reasons of conscience, morality or ethics

- Physicians must make medical records available to the patient, upon request pursuant to law, even if the physician is not participating in the EoLOA provisions

- Providing information or referral are not considered ‘participation’.
Participation in healthcare organizations

- Healthcare organization participation is voluntary
- Organizations may choose a level of participation that suits their needs and is in line with their own mission and values
- Organizations may prohibit employees from “participating” as defined in the Act. (443.15)
  - Exceptions: Providing information and referral (not considered participation)
Some Organization policy options

- **Embrace** ~ Full participation (e.g. protocols)
- **Educate** ~ Support or facilitate (e.g. make referral to supportive physician, staff actively involved)
- **Distance** ~ Referral only to source of information such as an advocacy group (staff not allowed to be involved)
- **Opt Out** ~ Refuse to allow staff to discuss, no physician referral, may include discharging patients who choose this option and sanctions for staff and providers
Levels of support

Full participation could include

• Designate social worker to explore request
• Established relationship with dispensing pharmacy
• Medical Directors write prescription
• Staff can be present at time of ingestion and fully support patient and family during the process
Optional levels of participation

Educate/Support could include
- Facilitate referral to supportive physician
- May or may not be present at ingestion
- Distance stance could include
- Refer to appropriate advocacy organizations
- Staff not present at time of ingestion

Opt-out
- Prohibition for staff participation, sanctions in place (see section 443.15)
What goes in the health record?

- All oral requests
- Written requests
- Attending physician diagnosis, prognosis, and all assessments
- Consulting physician’s diagnosis, prognosis and all assessments
- Any mental health assessment
- Record of offer to allow patient to rescind or withdrawal request
- Note that all requirements met
- Which drug(s) are dispensed
What goes to the CA. Department of Public Health?

- Copy of written request
- Attending physician check list and compliance form w drug & pharmacy information
- Consulting physician compliance form.

Later

- Final attestation by patient
- Follow up form from attending physician (<30 from death)
- Death certificate (automatic)
Payment and cost

To be determined for California
There will be variations
Private insurance providers will have their own polices
No federal dollars can be used to cover this option
  = Medicare, Veterans Administration
MediCal will probably cover care
Basic cost= 2-4 provider visits, plus drug
Developing best practices

EoLOA
• End of life care planning for all patients
• Family & care giver education
• Use of POLST forms
• Avoiding EMS intervention

Advance Care Planning
• Communities & Patients
• ACP SYSTEMS to incorporate Conversations into routine care
Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with Serious or Chronic, Progressive Illness *(at any age)*

Complete a POLST Form

Treatment Wishes Honored

**ACP Across the Continuum**

**Age 18**

Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with Serious or Chronic, Progressive Illness *(at any age)*

Complete a POLST Form

Treatment Wishes Honored
The death certificate:
By law, assisted death is not suicide

Source: Flickr user hisgett
Death Certificate

• The ACT is silent as to the cause of death to be listed
• Not Suicide
• List cause of death that is ‘most accurate’
• Act does not preclude listing ‘underlying terminal illness and or pursuant to End of Life Option Act’¹
  • Different from Oregon
  • Privacy

¹. On Call Brief Document 3459 CMA Legal Counsel January 2016
http://www.cmanet.org/resource-library/detail/?item=the-california-end-of-life-option-act
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Maintaining professionalism

- Understand your own position
- Know your employer’s position
- Decide in advance how you will approach this conversation
How do you know who is participating?

Resources and connections for participation

• Sharing of information and support among colleagues
• County medical associations
• CDHP 1-800 number: new legislation SB1002
• Advocacy agencies?
Demographics: OR Experience

- Who asks about aid-in-dying drugs or expresses a wish to hasten death?
- Why patients consider using aid-in-dying drugs
- *Usually not due to depression or other mental disorder*\(^1\)

### Data from the Oregon Death With Dignity Act 1998-2015

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>51% male / 49% female</td>
</tr>
<tr>
<td>Age at death</td>
<td>69.8% over 65, median 71 yrs</td>
</tr>
<tr>
<td>Race</td>
<td>96.6% Caucasian</td>
</tr>
<tr>
<td>Married or Domestic Partner</td>
<td>45%</td>
</tr>
<tr>
<td>Widowed</td>
<td>23%</td>
</tr>
<tr>
<td>Enrolled in hospice</td>
<td>90.5%</td>
</tr>
<tr>
<td>Insured</td>
<td>98.6%</td>
</tr>
<tr>
<td>Cancer</td>
<td>77.1%</td>
</tr>
<tr>
<td>ALS</td>
<td>8%</td>
</tr>
<tr>
<td>Lower respiratory disease</td>
<td>4.5%</td>
</tr>
<tr>
<td>Heart disease</td>
<td>2.6%</td>
</tr>
</tbody>
</table>

Source: Oregon Public Health Authority
https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx
Oregon DWDA: Patient diagnosis

Source: Oregon Public Health Authority
https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx
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Oregon DWDA: Prescription Recipients vs. Actual Deaths

Source: Oregon Public Health Authority
https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx

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**Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2015**

*As of January 27, 2016*

**Source:** Oregon Public Health Authority
https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx

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Medical aid in dying is not a failure of palliative care. Receipt of the medication may be a form of palliation.

<table>
<thead>
<tr>
<th>Patient Concern</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less able to engage in enjoyable activities</td>
<td>89.7%</td>
</tr>
<tr>
<td>Losing autonomy</td>
<td>91.6%</td>
</tr>
<tr>
<td>Loss of dignity</td>
<td>78.7%</td>
</tr>
<tr>
<td>Losing control of bodily functions</td>
<td>48.2%</td>
</tr>
<tr>
<td>Burden on family/friends/caregivers</td>
<td>41.1%</td>
</tr>
<tr>
<td>Inadequate pain control or fear of it</td>
<td>25.2%</td>
</tr>
<tr>
<td>Financial implications of treatment</td>
<td>3.1%</td>
</tr>
</tbody>
</table>

Source: Oregon Public Health Authority
https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx
Concerns over personal well-being

- Poor quality of life (present or future)
- Inability to pursue pleasurable activities
- Loss of control
- Loss of dignity
- Loss of meaning in life
- Desire for control of circumstances of death

Fear of future, worries over impact on others

- Being a burden
- Being dependent for personal care
- Fear of being a financial drain on family
Issues of declining health

• Loss of control of bodily functions
• Pain or physical suffering
• Fear of future pain and physical suffering


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Outcomes for family

Family members of patients who requested information on aid-in-dying drugs

• 95 requests for aid in dying, 56 prescriptions, 36 lethal ingestions

• Comparison group: family members of patients with cancer, ALS

Oregon family experiences

• More likely to believe that their loved one's choices were honored
• Fewer regrets about how the loved one died
• No differences in primary mental health outcomes of depression, grief, or mental health services use.
• Felt more prepared and accepting of the death

Pharmacy & Medication Issues
Medications*

High doses of barbiturates orally
• Secobarbital (Seconal) 10g in capsules
• Pre-medications to include anti-emetics [Zofran + Reglan (1hr before) and beta-blocker (15 min)]

Drug costs: Unknown in CA, could be as high as $3000.00-5000.00

Plan or insurance may or may not cover cost

*THIS INFORMATION IS NOT A MEDICAL PROTOCOL
Oregon data

Ingestion to death 2 h average, very occasionally over 24 hours range 5-34

No cases of waking in recent years (total 6/991 associated with underlying problem.)

27 of 218 in OR had a hospice nurse present at ingestion
Pharmacy issues

• Drug availability and pharmacy participation may vary
• Most pharmacies will develop polices and procedures
• Right to conscientiously object: Pharmacy businesses and individuals
• Counseling of patients
• Drug storage at home and drug disposal
• Legal concerns e.g. refusal to dispense
Conscientious practice is the action that comes of respecting one’s own moral beliefs while at the same time respecting the moral beliefs of others.

Make space for your own feelings, and those of others around you.
Conversations
How do you respond if asked about the End of Life Option Act

- **Know the facts:** who qualifies, physician involvement, specific forms to be completed, etc.
- **Be aware of your own values and beliefs.** Patients want to be respected and understood.
- **Know your employer’s position** on level of involvement, response to requests, referrals, conscientious objector or conscientious participant options.
Guidelines

• Clarify what the patient is asking

• A first request
  • a) does not require definitive refusal or acceptance
  • b) should prompt a discussion

• Meet the need for comfort & reassurance
• Make a plan with the patient
Putting requests in context

Why is the patient thinking along these lines?

- Need for information: Patient, provider
  - Shift from coping to planning
- Need for assurance that future suffering will be ameliorated
- Desire for ‘back up plan’
- Need for peace of mind
Areas of Exploration

- Expectations and fears
- Knowledge held, knowledge needed
- Suffering or physical symptoms
- Identifying patient goals
- Sense of meaning and quality in life
- Role of family or caregivers
- Spirituality
- Existential concerns
Questions for discussion

- What worries you most?
- Are you thinking about your own death?
- Have people close to you died? How did it go?
- How specifically would you like me to assist you?
- Are you suffering right now?
- What kind of pain/suffering concerns you most?
Understanding patient concerns

- How has your illness affected your family?
- What things still give you pleasure?
- How can we make the most of the time you have?
- Are there things you would like to do with the time you have remaining?

Living well now, in these moments, being truly alive until one is actively dying.
Tools to help with conversations
Resources from the California Medical Association

- My Health Care Wishes
- Advance Health Care Directive Kit
- Physician Orders for Life-Sustaining Treatment Kit (POLST)
Final Points

• Requests for or thoughts of hastened death can be common among those with advanced illness.
• Responding to requests can be emotionally challenging.
• Suffering is complex and personal. Take the time to understand the situation and you will be better prepared to address the needs of the patient.

Final Points

The Forest and the Trees

Take advantage opportunities for exploration and discussions about end of life care planning for all patients with serious or terminal illness.
Learn more.

- **Conversation Skills for End of Life Care Planning.**
  May 31, 2016 Sacramento

- **End of Life Option Act: Overview and Discussion**
  Webinar 12pm-1pm June 7

- **POLST: It Starts with a Conversation**
  July 14-15, 2016 San Francisco

- CCCC & CSU PCI online training in advance care planning

- See our website for complete details – [www.coalitionccc.org](http://www.coalitionccc.org)
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**Contact:** 916-489-2222  
[info@coalitionccc.org](mailto:info@coalitionccc.org)  *(Attn: Consulting)*