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# CALIFORNIA END OF LIFE OPTION ACT

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# 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
  - http://www.ucconsortium.org/portfolio-view/end-of-life-care-act-fact-sheet/

End of Life Option Act Task Force



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# 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.*



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# 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



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# Acknowledge the road.




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# In context

Patient Autonomy
Shared decision making
Beneficence vs non-malficence
Personal integrity
Professionalism



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# AB X2-15: The End of Life Option Act

Terminology

- Physician assisted death/dying (PAD)
- Medical aid in dying
- Aid in dying drug



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# 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**



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# 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



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# Participation and eligibility

- **No provider, healthcare worker or organization is required to participate or to refer patients**
- **Not all providers or patients CAN participate**



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# 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



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# 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*.



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# 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



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# 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



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# 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



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# 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



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# 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



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# 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*



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# 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'.**



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# 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)



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# 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



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# 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



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# 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)



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# 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



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# 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)



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# 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



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# 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



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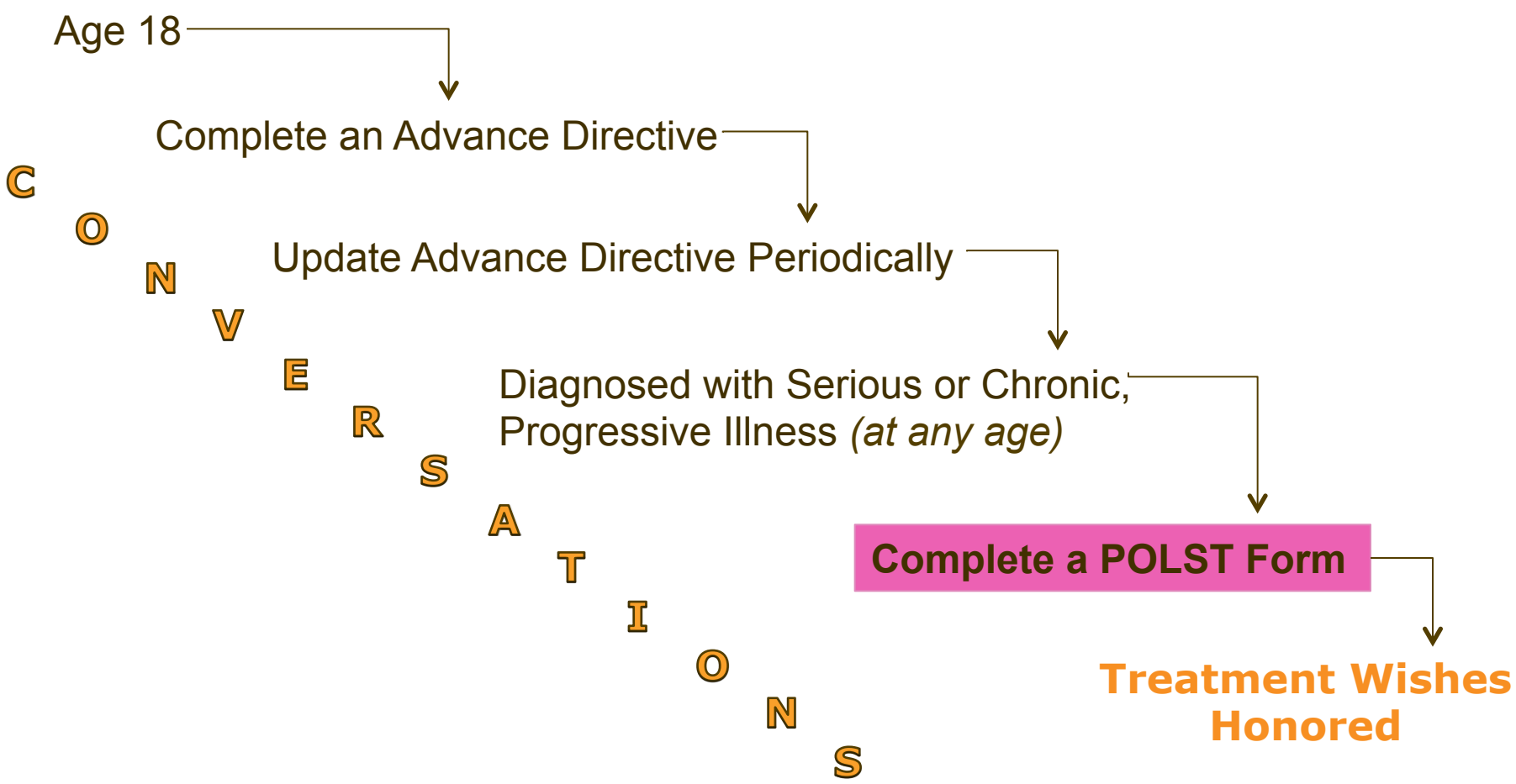
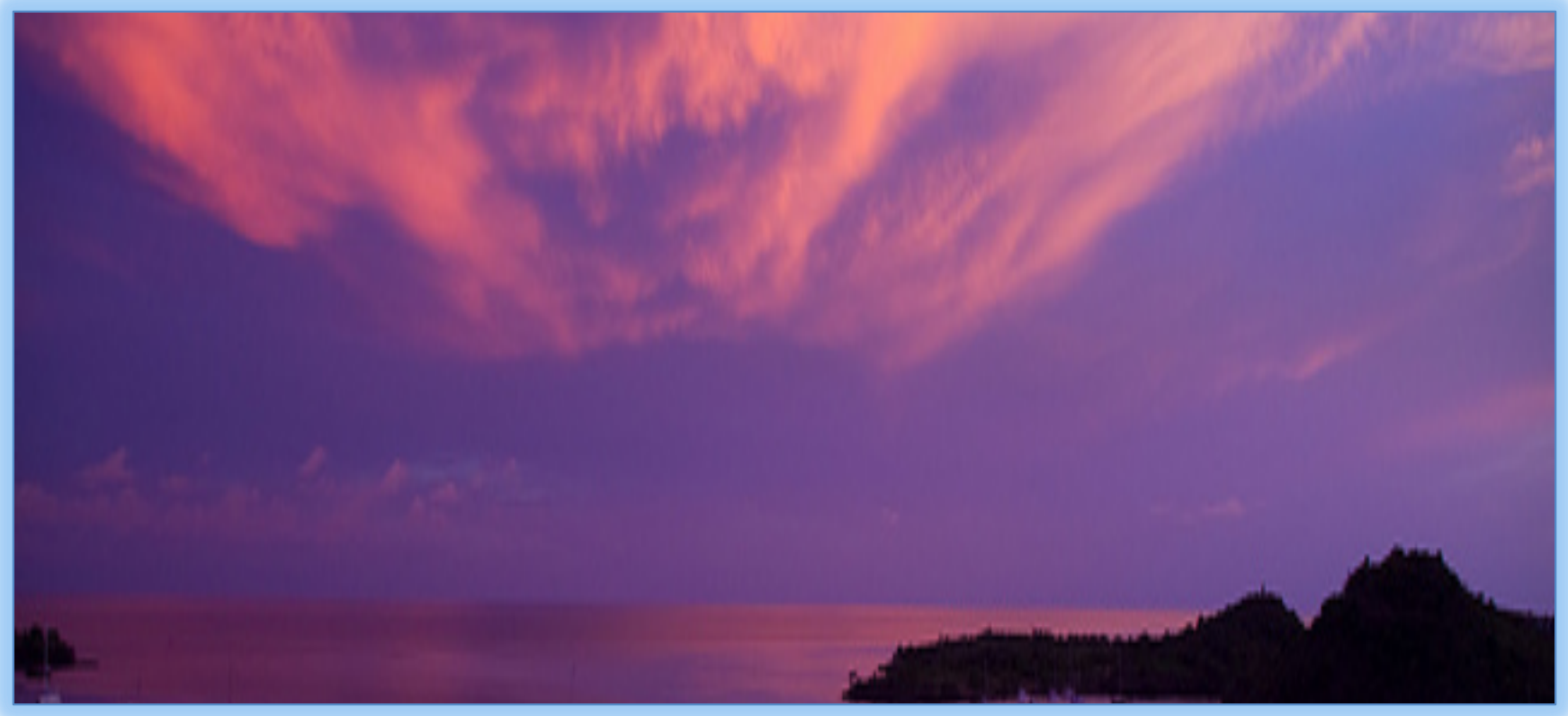
# ACP Across the Continuum




*CCCC perspective on Advance Care Planning*

# The death certificate:

# By law, assisted death is not suicide



***Source:*** *Flickr user hisgett*



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# 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



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# 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?



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# 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]

Ganzini, L., Nelson HD, Schmidt TA, Kraemer DF, Delorit MA, Lee MA, *Physicians' Experiences with the Oregon Death with Dignity* Act NEMJ 342(2000):557-63. Block SD, *Assessing and managing depression in the terminally ill patient*. Ann Int Med 132(2000)209-18.



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

| | |
|---|---|
| Gender | 51% male / 49% female |
| Age at death | 69.8% over 65, median 71 yrs |
| Race | 96.6% Caucasian |
| Married or Domestic Partner | 45% |
| Widowed | 23% |
| Enrolled in hospice | 90.5% |
| Insured | 98.6% |
| Cancer | 77.1% |
| ALS | 8% |
| Lower respiratory disease | 4.5% |
| Heart disease | 2.6% |

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



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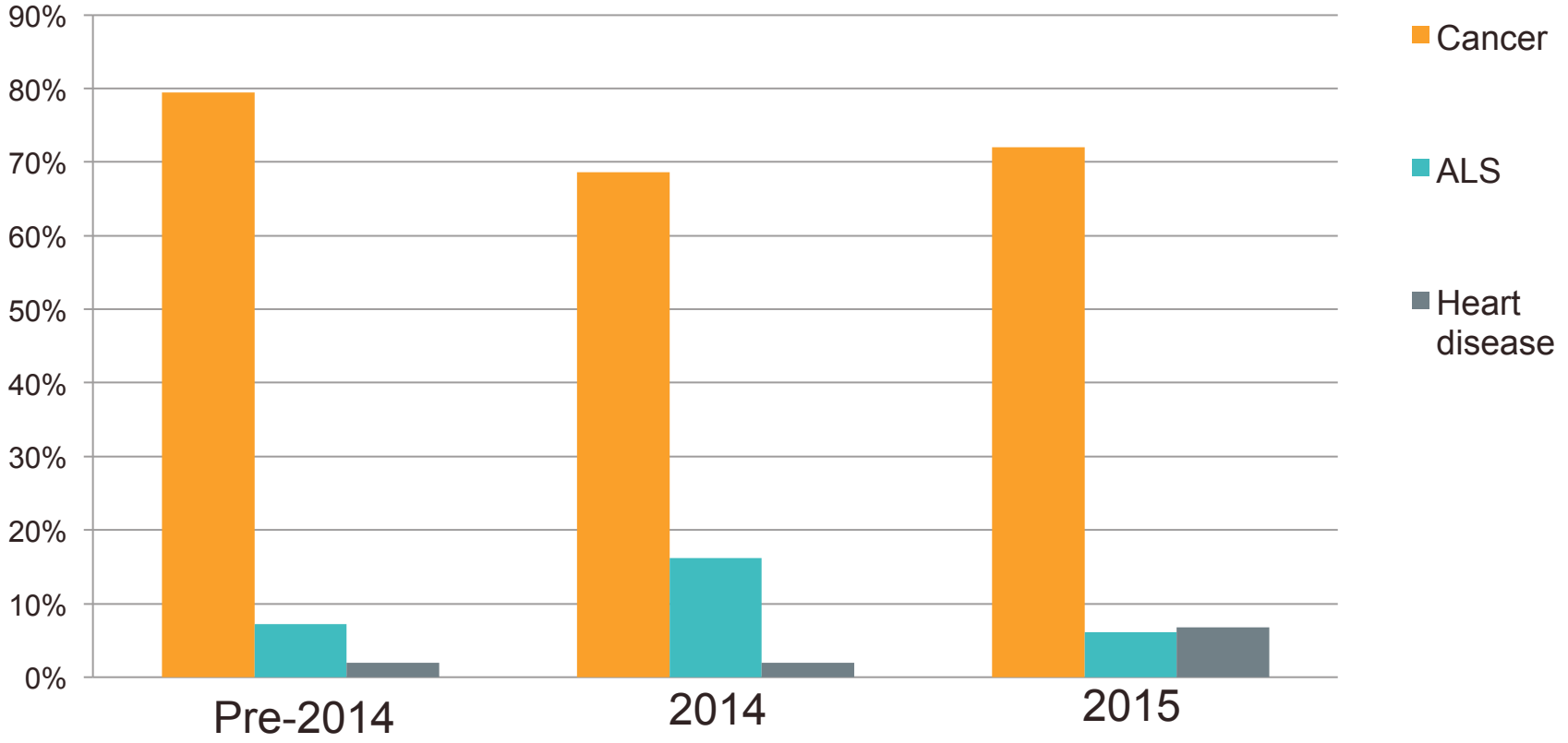
# Oregon DWDA: Patient diagnosis




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



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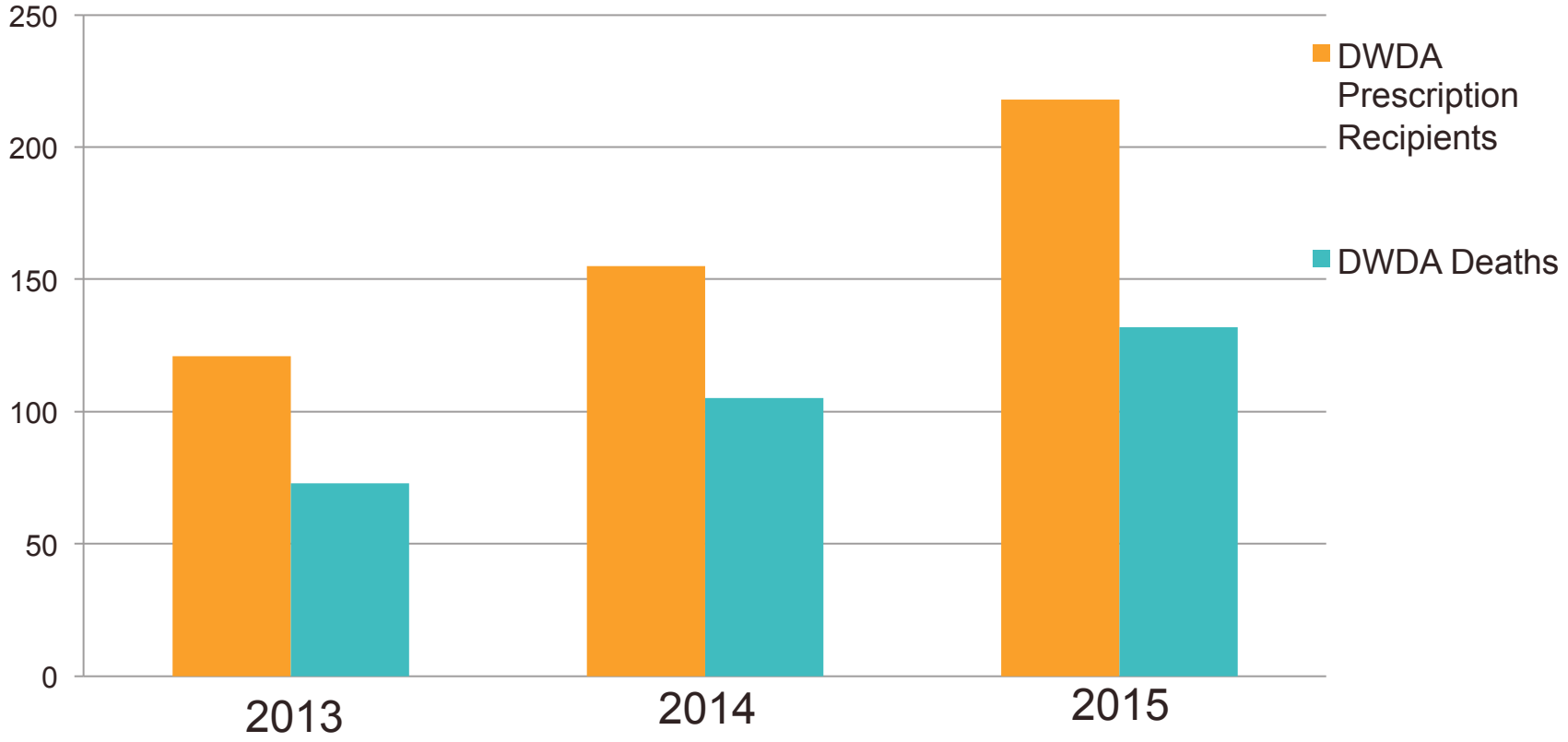
# Oregon DWDA: Prescription Recipients vs. Actual Deaths




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



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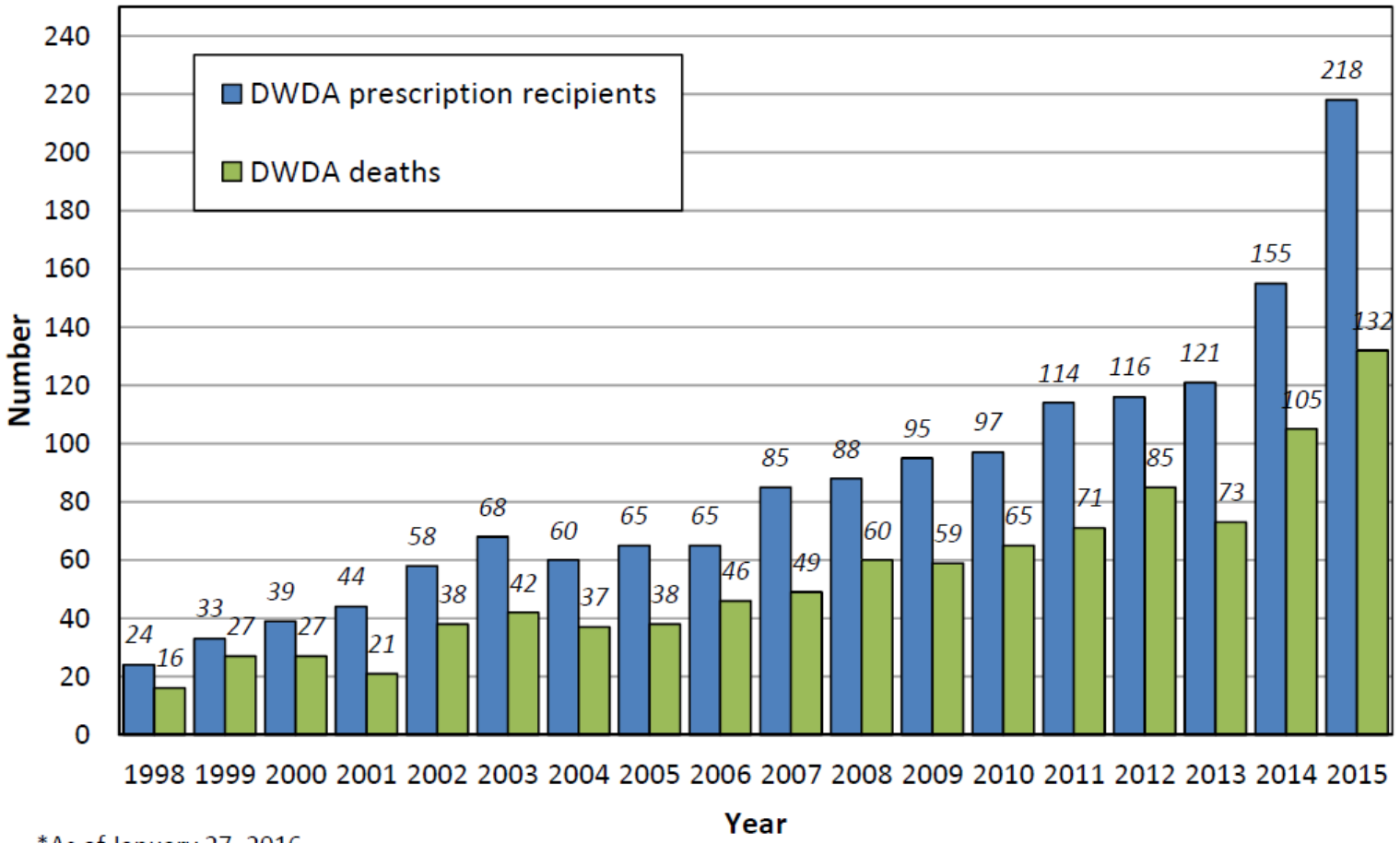
# Figure 1: DWDA prescription recipients and deaths*, by year, Oregon, 1998-2015




*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.



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# Aid-in-dying drug requests: Oregon experience 1998-2015

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

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



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# 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

McPhee, S.J., Winker, M.A., Rabow, M.W., Pantilat, S.Z., Markowitz, A.J., (Eds.) (2011) *Care at the close of life: Evidence and experience.* McGraw Hill Medical



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# Fear of future, worries over impact on others

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

McPhee, S.J., Winker, M.A., Rabow, M.W., Pantilat, S.Z., Markowitz, A.J., (Eds.) (2011) *Care at the close of life: Evidence and experience.* McGraw Hill Medical



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# Issues of declining health

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

McPhee, S.J., Winker, M.A., Rabow, M.W., Pantilat, S.Z., Markowitz, A.J., (Eds.) (2011) *Care at the close of life: Evidence and experience.* McGraw Hill Medical



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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

Ganzini L, Goy ER, Dobscha SK, Prigerson H. Mental health outcomes of family members of Oregonians who request physician aid in dying. J Pain Symptom Manage. 2009 Dec;38(6):807-15. doi: 10.1016/j.jpainsymman.2009.04.026.



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# 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

Ganzini L, Goy ER, Dobscha SK, Prigerson H. Mental health outcomes of family members of Oregonians who request physician aid in dying. J Pain Symptom Manage. 2009 Dec;38(6):807-15. doi: 10.1016/j.jpainsymman.2009.04.026.



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# Pharmacy & Medication Issues



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CHILDREN'S HOSPICE & PALLIATIVE CARE COALITION

# 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*



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# 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



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# 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

# Ethics and aid-in-dying drugs

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.

Task Force to Improve Care of Terminally-Ill Oregonians.The Oregon Death With Dignity Act: *A Guidebook for Health Care Professionals. http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/ethics-outreach/upload/Oregon-Death-with-Dignity-Act-Guidebook.pdf*



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# Conversations



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# 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.



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# 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



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# 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



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# 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



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# 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?



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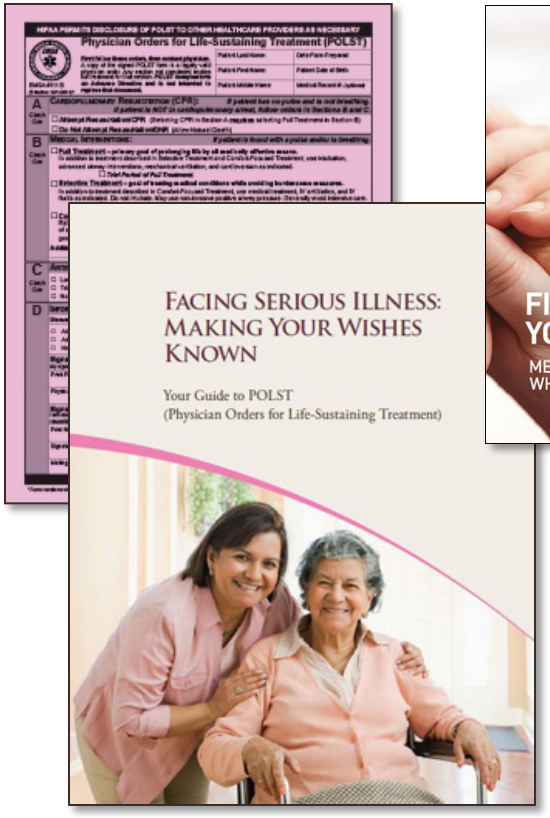
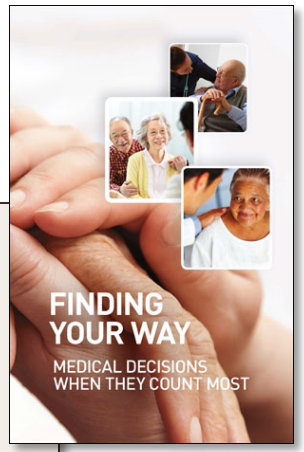
# Understanding patient concerns

- 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



**CoalitionCCC.org/store**



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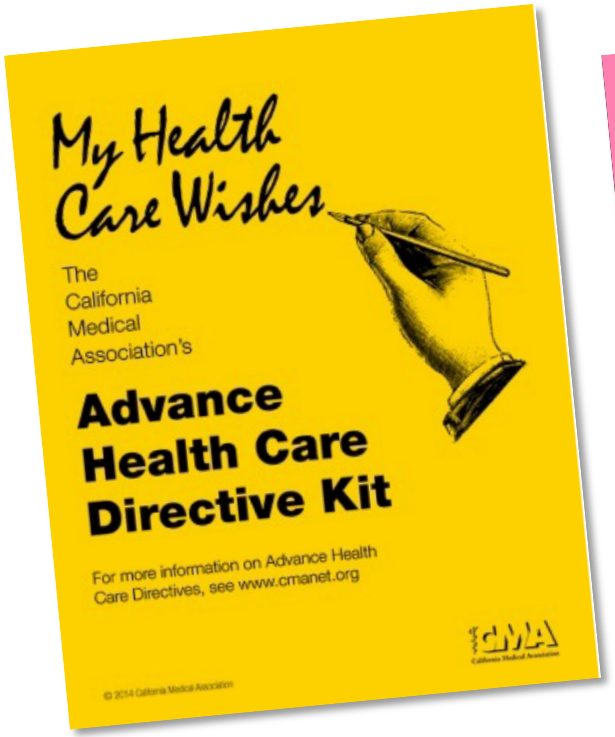
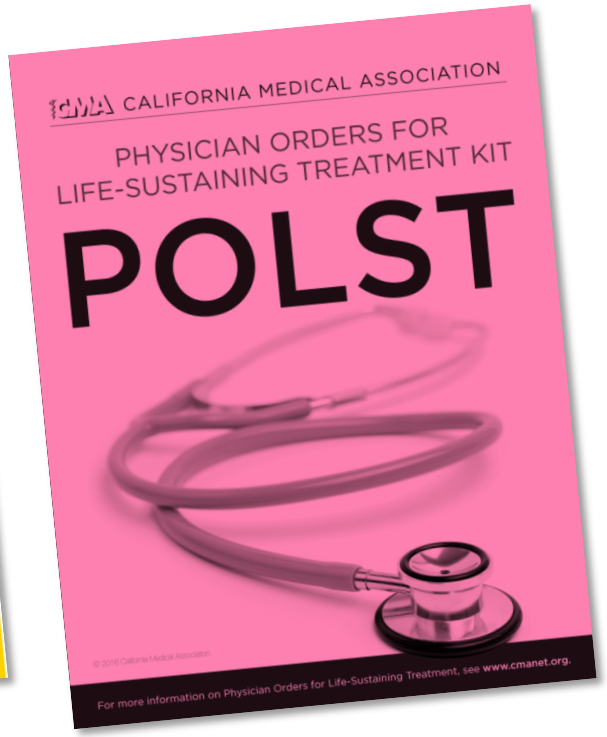
# Resources from the California Medical Association



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# 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.

Gallagher R. Can't we get this over with? An approach to assessing the patient who requests hastened death. Canadian Family Physician 2009 Vol. 55:260-261



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# 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.



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# 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



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# Let us bring training and expertise to you

**CCCC consulting service**

- Brings education to your organization
- **Customizes trainings to fit your schedule, geographic and cultural needs**
- Topics include **POLST**, advance care planning, palliative care, conversation skills, cultural sensitivity and more

**Contact:** 916-489-2222

info@coalitionccc.org *(Attn: Consulting)*



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