Medical Aid-in-Dying (MAID) Final Report

Joint Commission on Health Care

August 22, 2018 Meeting

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Study Mandate

- Delegate Kaye Kory requested via letter that the JCHC study the issue of Medical Aid-in-Dying (MAID). The delegate asked that the study include a review of states that currently authorize MAID and address the following questions:
  - What has been the impact of informing patients about end-of-life options such as hospice care and palliative care?
  - In current MAID states, how have health care systems, institutions and providers acted to implement the law?
  - In current MAID states, have people been coerced to ingest end-of-life medication?
    - Have any of the states enacted protections to discourage or prevent coercion?
  - Has the implementation of the law impacted any state's health care costs?
  - Using data from states that allow MAID, how many people would likely utilize MAID if it became law in Virginia?
- JCHC members approved the study during the Commission's May 23, 2017 work plan meeting

3

Final Report of Two-Year Study

- Please see the appendix for a copy of the interim report on Medical Aid-in-Dying presented in August, 2017
- Study mandate questions answered in the interim report are not discussed in this final report

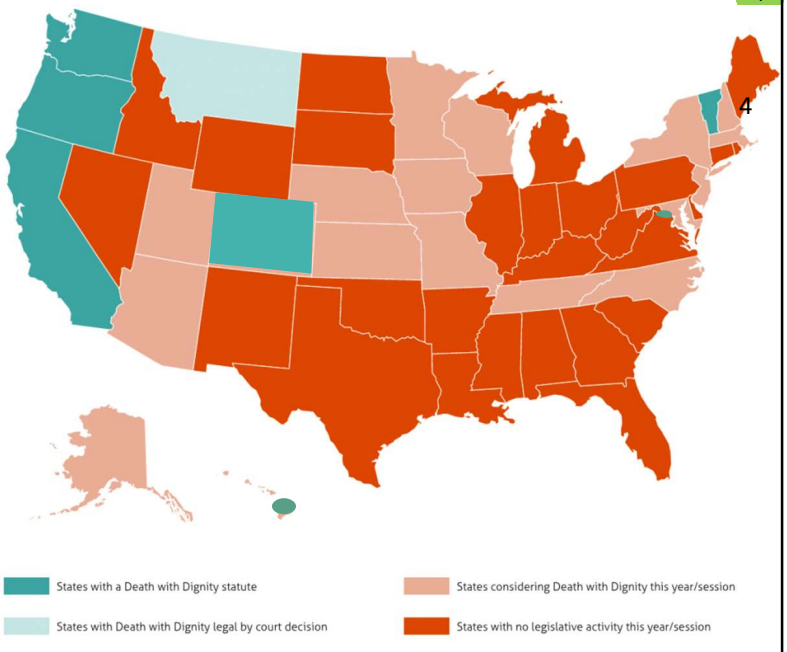
4

MAID – U.S. Landscape

States with MAID Laws:
Oregon (1998)
Washington (2008)
Vermont (2013)
California (2016)*
Colorado (2016)
Washington, D.C. (2017)
Hawaii (2018)

By Judicial Review:
Montana (2009)

*5.24.18: Judge overturns law; 6.15.18: Judgement is stayed in appeals court. Now legal pending further litigation.



https://www.deathwithdignity.org/news/2016/03/state-progress/ [Updated by M. Chesser]

5

MAID Study Work Group

- As was mentioned during the interim report, a work group was created to discuss Medical Aid-in-Dying
  - Discussions focused primarily on the reasons to support/oppose MAID, the preferred name of the practice (e.g. MAID vs. Physician Assisted Suicide) and, using Oregon statute as a blueprint, the many components that should be included or removed from the language of any potential Virginia statute
    - It was established that, for members who oppose MAID, working on language for potential Virginia statute does not indicate support for MAID
  - Six meetings were held with approximately 20-30 participants per meeting
- I would like to thank:
  - All of the individuals who kindly gave their time and made the effort to participate in the work group
  - Andrew Mitchell, JCHC analyst, for a great job organizing and facilitating the last year of work group meetings

6

Informing Patients About End-of-Life Options Such as Hospice and Palliative Care

- All MAID statutes require that both the attending and consulting physician inform the patient about end-of-life options, including hospice and palliative care
- In the states with available data, the great majority of MAID users already were enrolled in hospice and/or had access to palliative care
  - Oregon: 88.7% (2016); 90.4% (1998-2015)
  - Washington: 77% (2016); 81% (2015); 69% (2014)
  - California: 83.8% (2016) received hospice and/or palliative care
  - Colorado: 92.9% (2017)*
- A 2017 study [1] of Kaiser Permanente Southern California's MAID program showed that of the 68 individuals who died of MAID
  - 34 (50%) had palliative care at time of MAID *inquiry*; and the median length of time since first exposure to palliative care services prior to inquiry was 103 days (with a range of 72-397 days)
  - 38 (56%) had hospice care at time of MAID *inquiry*; and the median length of time on hospice prior to inquiry was 23 days (with a range of 4-65 days)
  - Although the study did not provide data on hospice/palliative care rates at time of death, California's overall rate of 83.8% suggests that additional individuals began receiving hospice and/or palliative care after inquiring about MAID
- Legalization of MAID has not resulted in a decrease in use of hospice or palliative care[2]

* Note: Colorado death data is comprised of individuals who were prescribed MAID medications. Law does not require follow-up data, so the number that died of MAID vs some other cause is unknown. 1. Nguyen et al 2017; 2: Cain 2016, Jackson 2008, Nguyen et al 2017, Each MAID state Data Report

Informing Patients About End-of-Life Options Such as Hospice and Palliative Care

7

- Studies of Oregon show that palliative care services spending and patient satisfaction have risen since 1998, when MAID became legal[1]
  - Researchers hypothesized that the request for information on MAID leads to conversations between patients and their physicians about a range of end-of-life options[2]
- In 2000, a survey of Oregon physicians who had been asked for MAID medication from a patient produced the following results[3]
  - 31 of 67 patients for whom a substantive intervention was made changed their minds about wanting a prescription compared to only 11 of 73 patients for whom no substantive intervention was provided
  - Substantive interventions included: "control of pain and other symptoms; referral to a hospice program; general reassurance and *specific reassurance that the prescription would be made available*; treatment of depression; a social work consultation resulting in the provision of services to the family; *an alternative means of hastening death*; and a palliative care consultation"
  - Once patients were informed of hospice and enrolled, six percent chose to not use the medication
    - Note that, on average, approximately 1/4 to 1/3 of all individuals who receive a MAID prescription do not use it[4]

1: Cain 2016; 2. Dobscha et al. 2004; 3: Ganzini et al. 2000; 4. Clinical Criteria for PAD document 2015, and each MAID state data reports

In MAID states, how have health care systems, institutions and providers acted to implement the law?

8

- The last 20 years of research show a wide variation in implementation policies/practices among health care systems, hospitals, hospice and palliative care programs and physicians
- The majority of researchers conducting studies in MAID states have found that physicians, nurses, social workers, clergy and others in health care systems, institutions or private practice want and need education and guidance on MAID
  - Some MAID-providing entities have given employees education and/or training on MAID and clear guidelines to follow while others have not
- In 2012, Compassion and Choices convened the Physician Aid-in-Dying Clinical Criteria Committee to create guidance for physicians willing to provide MAID to eligible patients*
  - Committee included experts in medicine, law, bioethics, hospice, nursing, social work and pharmacy*
  - To view Clinical Criteria document, please go to: https://www.compassionandchoices.org/wp-content/uploads/2016/02/CPG-Supplemental-Data-2015.pdf

*Orentlicher et al 2016

Example of Implementation Challenges: Stanford Health Care, California

9

- Initial experiences highlighted multiple challenges with formal implementation, especially in regard to the disjuncture between an organizational commitment to participate and the legal and ethical right of employees to opt-out
- Their policy on conscientious objection requires that the physician maintain indirect involvement with the patient and an institutional commitment to finding an alternative physician; however, difficult due to stigma concerns and challenge of establishing care and prescribing for a colleague's patient
- Challenges in distinguishing between conscientious objection and clinical judgment
  - Example: MAID vs. cessation of parenteral nutrition
  - Conference between an ethics consultant, a palliative physician and the attending oncologist resulted in conclusion that the physician's opinion about the inappropriateness of MAID was a clinical judgement, not conscientious objection
- Participating institutions "should develop appropriate mechanisms to review, evaluate, and provide real-time guidance to help address such challenges" (p.908)

Please note: Slide content includes language that is very close to being a direct quote. Source: Harman and Magnus 2017

Example of Implementation: Seattle Cancer Care Alliance, Washington

10

- Policy written by medical director and approved by simple majority of Medical Executive Committee members
- Created informational packets for patients, physicians, and patient advocates
- Does not accept new patients solely for MAID, instead referred to Compassion and Choices
- Does not post the Death with Dignity (DWD) Act or their program in public places
- Prior to implementation they offered an institution-wide education program and surveyed clinicians to determine willingness to be a provider (determined to be sufficient number to implement program)
- Interested patient is assigned a Patient Advocate

Please note: Language on this and the following three slides was obtained from Loggers et al. 2013

The Patient Advocate: 11
Assists the patient, family members, pharmacist, and physicians throughout the process
Tracks required documentation compliance (sent to Washington Department of Health)
Describes the DWD process and the alternatives (specifically, palliative care and hospice, with these services offered as additions to, or in lieu of, DWD)
Assesses the patient's rationale for and interest in further participation
If patient elects to participate in the program, the advocate conducts a preliminary chart review to confirm documentation of the terminal prognosis or, if absent, to request that the attending physician document the prognosis explicitly
Determines whether the attending physician will act as the prescribing physician. If not, the advocate identifies a prescribing physician and a consulting physician from the list of willing providers, preferentially choosing physicians who specialize in the patient's type of cancer
Formally documents the patient's request for assistance with dying and provides the patient with written information that describes the program (including a timeline of the required requests, assessments, and waiting periods), which must be signed by the patient
Verifies that the patient is a Washington resident and completes a psychosocial assessment. Social workers provide the first line of psychological evaluation for all patients, regardless of whether or not they are participating in the DWD program, using interview-based techniques and standardized assessments. Although physicians retain the responsibility to evaluate patients for depression and decision-making capacity, advocates make these assessments as part of their standard practice. Advocates refer patients to the Psychiatry and Psychology Service if there is any history of, or positive screening for, a mental health disorder or impaired decision-making capacity.
The advocate then collects copies of the Physician Order for Life-Sustaining Treatment and health care directives, assisting in their completion if desired

The Patient Advocate: 12
Arranges for a clinician to be present at the time of medication ingestion, if requested (this is rare)
Provides advice regarding the securing and disposal of unused medication
Provides grief support and legacy support (e.g., help in preparing letters or videos by which to be remembered) through periodic calls or visits
Requests that the family inform SCCC when the patient ingests the medication, so that staff can provide assistance in the case of complications, offer bereavement support, and aid the prescribing physician in completing the required after-death reporting forms
Participates in two in-person meetings with the patient and family on average (range, one to four); and use of telephone follow-up is possible

Example of Implementation: Seattle Cancer Care Alliance, Washington (Cont'd)

13

- The patient (and family) meets sequentially with the prescribing clinician and the consulting clinician to review the medical diagnosis, prognosis, risks of medication, and alternatives (including palliative and hospice care)
- After the mandatory waiting period of 15 days, if all requirements are met, a written prescription is given to the SCCA retail pharmacy. The pharmacist schedules a private room to meet with the patient (and family) in order to discuss preparation of the drug for ingestion, potential side effects, and the use of antiemetic therapy
- Checklists and medical charts are randomly audited annually by the director of supportive care and specialty clinics
- They have had 100% compliance with the completion of mandated forms and processes, with the exception of one unintentional failure to observe the full waiting period early in our program
- "Our Death with Dignity program has been well accepted by patients, families, and staff"
  - Due to: professionalism of advocates, "great care taken by our prescribing and consulting clinicians when interacting with patients and families", low profile of the state program, willingness of leadership to allow "considerable debate" before the program was developed (p.1422)
  - Some of the physicians that originally opposed the program later agreed to participate

How MAID Law Has Been Implemented by Hospice Programs

14

- A 2012 study by Campbell and Cox indicated that most Oregon hospice programs set programmatic, professional, and moral boundaries to their involvement in MAID deaths
  - For example: due to post-ingestion complications, primarily regurgitation, in 1 in 20 cases, several hospices developed policy that staff can address "human" needs regarding comfort and safety (e.g. providing anti-nausea medication), but not "medical" needs (which are the domain of the physician)
- Another study found that limits were set regarding "(a) providing information to the patient, (b) notifying the primary physician of the patient's request, (c) providing or assisting with the medications necessary to hasten a patient's death, and (d) permitting the presence of staff members at ingestion or death."*

*Norton and Miller 2012

15

Coercion and Fraud

- Penalties for coercion and fraud included in statute:
  - Oregon: Class A felony
  - Washington: Class A felony
  - Vermont: Unable to find section on coercion/fraud
  - California: A felony
  - Colorado: Class 2 felony
  - D.C.: Class A felony
- Unable to find cases of substantiated accusations of fraud or coercion
- One can assume it is likely that at least some instances of coercion or fraud in MAID states have occurred; however…
  - It may not have been witnessed or interpreted as coercion or fraud
  - substantiating the claim may not have been successful

16

Has the implementation of the law impacted any state's health care costs?

- States are not allowed to use federal Medicaid or Medicare funds to pay for MAID services
  - As a result, some states utilize state funds to pay for MAID among Medicaid enrollees
  - However, given the relatively low cost of MAID medications and additional physician visits required during the MAID process coupled with the very low percentage of individuals participating in MAID who also are enrolled in Medicaid, cost to the state is minimal

17

Recommended Statute Language if Legislation is Introduced in Virginia

18

Statute Language: Areas of Work Group Member Disagreement*

- Term used in statute (e.g. MAID vs Physician Assisted Suicide)
- Accuracy of "terminal illness (likely death in ≤ 6 months)" language
- Overall, balance in language between safeguards and access to MAID
- Requirements necessary to recognize and prevent individuals from using MAID whose judgment is impaired by depression
- Potential for discrimination against the disabled and other vulnerable groups
  - For example, use of the term *self-administer* vs. *ingestion*
- Need for additional language to further decrease the likelihood of coercion
- Definition of informed decision
- Voluntarily expressing wish to die (relating to forms of communication)

*Please see in appendix "10 Reasons to Oppose Physician Assisted Suicide" slides and go to https://www.compassionandchoices.org/ for examples of arguments in opposition to and in support of MAID

MAID Component (MAID State Statutes That Include It)

19

Attending MD Requirements

Confirm Patient Eligibility

- Requesting individual must:
  - Be 18+ years old (all 6)
  - Be State resident (all 6)
  - Be capable of decision making (all 6)
  - Voluntarily express wish to die (all 6)
  - Have a terminal illness (likely death in ≤ 6 months) (all 6)

Ensure Informed Consent

- Inform patient of:
  - Diagnosis and prognosis (all 6)
  - Risks and probable result of MAID medication (all 6)
  - Alternatives including comfort care, hospice, pain control (all 6) and treatment available for terminal disease (VT)
  - His/her right to rescind request at any point (all 6)
  - Possibility that patient can obtain MAID medication but not take (CA, CO)
- Confirm that decision is not coerced through a private conversation (CA, CO)
- Refer to 2nd physician for confirmation (all 6)
- Refer to counseling if determined to be appropriate (if indications of mental impairment [CA]) (all 6)

Provide information on process

- Recommend patient notify next of kin of request (OR, CA, DC, WA)
- Counsel patient about having another person present when taking medication and not taking in a public place (OR, CA, CO, DC, WA)
- Counsel patient on enrolling in hospice (CA)
- Counsel patient on storing medication safely (CA, CO)
- Offer patient opportunity to rescind at 2nd oral request (OR, CA, DC, VT, WA)
- Give patient final attestation form to be completed/signed ≤ 48 hours of self-administering MAID medicine (CA)

MAID Component (MAID State Statutes That Include It)

20

Prescribing/ Dispensing

- Verify patient is making informed consent immediately prior to writing prescription (all 6)
- No prescription to be filled if psychiatric or psychological illness present (OR, CA, CO, DC, WA)
- No prescription to be filled if patient has not made voluntary/informed decision (OR, CA, CO, DC, WA)
- Dispense MAID medication directly or, with patient's written permission, via pharmacist to patient or designated agent (all 6)

Other

- Attending MD, consulting physician, mental health providers may not be related to patient or entitled to patient's estate (CA)

Fulfill reporting and documentation requirements

- Must document in patient's medical record:
  - All oral/written requests by patient (all 6)
  - Diagnosis, prognosis, verification that patient is capable, acting voluntarily, making informed consent (by attending and consulting MDs) (all 6)
  - Outcome of counseling, if performed (all 6)
  - Offer to patient to rescind request (all 6)
  - Note that all requirements have been met and medication prescribed (all 6)
  - Final attestation form signed by patient, returned to attending MD, for inclusion in medical record (CA)
  - Attestation that patient enrolled in hospice or informed of EOL services (VT)
  - Submit records to health authority (CA, DC, VT) ≤ 30 days of writing prescription of patients death (CA, DC)
  - Records exempt from disclosure (CA, CO, WA)
  - May sign death certificate indicating disease as cause of death (all 6)

Consulting MD responsibility

- Examine patient, medical records (all 6)
- Confirm in writing attending MD diagnosis (all 6)
- Verify patient is capable and acting voluntarily (all 6)
- Refer to counseling if appropriate (all 6)

MAID Component (MAID State Statutes That Include It)

21

Patient requirements

Form of request
- Make oral and written requests (all 6) directly to attending MD (CA)
- Written request substantially in form provided in Statute (OR, CA, CO, DC, WA), must use form in statute (CA)
- Written request signed/dated with 2 witnesses (all 6), given directly to MD (CA)
- 2nd oral request to attending MD ≤ 15 days after initial (all 6)
- Attending MD cannot write prescription until ≥ 15 days after initial oral request and ≥ 48 hours after written request (OR, DC, VT, WA)

Witness requirements
- ≥ 2 adults (all 6)
  - witnesses personally known or provided patient ID (CA)
- Only 1 witness may be (CA)
  - Related by blood, marriage, adoption (all 6)
  - Heir (OR, CA, CO, DC, WA)
  - Owner/operator/employee of facility where patient treated (CA)
  - 0 witnesses may be attending MD, consulting physician, mental health specialist (CA)
  - If patient in nursing facility, 1 witness may be person designated by facility (0)
  - Witnesses attest that patient is capable, acting voluntarily, not coerced (all 6)

Other

Regulatory follow-up and public reporting requirements
- Oversight agency will:
  - Adopt rules to facilitate collection of information re: compliance (OR,CO, DC, VT, WA)
  - Generate and make public annual statistical report of information collected, adhering to HIPA (OR, CA, CO, DC, WA)
  - Provide an online guidebook and establish training opportunities for medical community to learn about the MAID process and medications that may be used
- Rules for safe disposal of unused meds by persons in custody of meds (CA, CO)

MAID Component (MAID State Statutes That Include It)

22

Immunities
- Immune from civil or criminal prosecution for any person solely for being present when patient takes medication (all 6)
- Providers are immune from disciplinary action, revocation of licenses/privileges for prescribing lethal meds under terms of law (all 6)
- No provider compelled to participate (other than transferring records) (all 6)
- Provider can prohibit other providers (employees, contractors) from participating on facility premises/acting under providers' employment if written policy in place and provider notified (all 6)
- Provider cannot prohibit independent contractors/employees from participating outside scope of contract/employment or off premises (OR, CA, DC, VT, WA)
- Sanctions can be imposed on providers participating against policy (all 6)
- No effect on life or health insurance policies or annuities; health care service plan contract (CA) or health benefit plan (CA) (all 6)
- No effect on will, contract, other agreement (OR, CA, CO, DC, WA)
- Does not sanction mercy killing, active euthanasia, lethal injection (all 6)
- Actions under law ≠ suicide, assisted suicide, homicide (all 6)
- Participation ≠ elder abuse, neglect (OR, CA, CO, WA)

Liabilities
- Forging prescription, coercion into request, concealing or destroying rescission of request is Class A felony (OR, CA, DC, WA)
- Administering medicine to individual without consent is felony (CA, CO, DC)
- Government can make claims against individual if death occurs in public place causing expenses (all 6)

23

Additional Options to Consider

Improving End of Life Care in Virginia

Note: The following six slides (or some slide content) are used with permission from the Virginia POST Collaborative and Capital Caring

24

Most Adults Don't Have Any Advanced Care Planning Documents…

- Only 25% of adults have advance directives
- What happens if there is no plan?
  - State determines the legal health care decision maker
  - Medical treatments are not limited in an emergency
  - Decision makers, families, health care providers struggle to determine what the patient would want
  - Often this leads to…

25

I Want Everything Done (or the presumption of this desire)

26

Virginia Physician Orders for Scope of Treatment (POST)

- The Virginia Physician Orders for Scope of Treatment (POST) Form Set is a portable medical order that, in the intended population as identified by the National POLST Paradigm, is recognized as a medical best practice for eliciting, documenting and honoring a patient's medical wishes
- Virginia's POST Program received endorsement from the National POLST Paradigm in 2016 (the 19th state to earn this recognition)
- The POST form set is intended to be used during a time of advanced illness
- Unlike an Advance Directive (signed by patient) and Do Not Resuscitate directive (signed by provider), the POST form set is **created during a conversation** between the physician and patient/patient agent (if patient is unable to communicate) and signed by the patient/patient agent and the physician
- Unlike the AD, which usually is created, most often, earlier in one's life and then held in suspension, the POST form set is created when a person is determined to have serious illness; therefore, it can provide specific orders within that context with the specific illness/condition in mind
  - As a result, it is considered to be an important addition to an AD or DNR

Sources: Hickman and Critser 2018; POST Collaborative slide content; and communication with Dr. Matt Kestenbaum (Virginia POST) and National POLST Paradigm staff

27

HIPAA permits disclosure to health care professionals and authorized decision makers for treatment

Virginia Physician Orders for Scope of Treatment (POST)

This is a Physician Order Sheet based on the patient's current medical condition and wishes. Any section not completed creates no presumption about the patient's preferences for treatment.

Name Last / First / M.I.

Address

City / State / Zip

Date of Birth (mm/dd/yyyy) | Last 4 Digits of SSN ☐☐☐☐

A ✓one only

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ Attempt Resuscitation ☐ Do Not Attempt Resuscitation (DDNR/DNR/No CPR)

If "Do Not Attempt Resuscitation" is checked, this is a DDNR order. See Page 2 for instructions for use.

If a previous Durable Do Not Resuscitate form or POST form indicating Do Not Attempt Resuscitation was signed by the patient, only the patient can consent to reversing such a Durable DNR Order.

When not in cardiopulmonary arrest, follow orders in B & C

B ✓one only

If "Attempt Resuscitation" is checked in Section A, Virginia EMS protocol includes intubation when needed.

MEDICAL INTERVENTIONS: Patient has pulse and / or is breathing.

☐ **Comfort Measures:** Treat with dignity and respect. Keep warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Transfer to hospital *only* if comfort needs cannot be met in current location. Also see "Other Orders" if indicated below.

☐ **Limited Additional Interventions:** Includes comfort measures described above. Do not use intubation or mechanical ventilation. May consider less invasive airway support (e.g., CPAP or BiPAP). Use additional medical treatment, antibiotics, and cardiac monitoring as indicated. Hospital transfer if indicated. Avoid intensive care unit if possible. Also see "Other Orders" if indicated below.

☐ **Full Interventions:** In addition to Comfort Measures above, use intubation, mechanical ventilation, cardioversion as indicated. Transfer to hospital if indicated. Include intensive care unit. Also see "Other Orders" if indicated below.

Other Orders: _____

C ✓one only

ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and fluids by mouth if feasible.

☐ **NO** feeding tube (Not consistent with patient's goals given current medical condition)

☐ Feeding tube for a defined trial period (specific goal to be determined in consultation with treating physician)

☐ Feeding tube long-term if indicated

Other Orders: _____

28

Other Orders: _____

D

Must be signed by a physician, nurse practitioner or physician assistant

PROVIDER SIGNATURE: My signature below indicates that I have discussed the decisions documented herein with the patient or the person legally authorized to consent on the patient's behalf and have considered the patient's goals for treatment to the best of my knowledge.

DISCUSSED WITH (Required):

☐Patient ☐Agent named on Advance Directive ☐Other person legally authorized ☐Court appointed guardian

SIGNATURE (REQUIRED): _____ **DATE (REQUIRED):** _____

PROVIDER NAME (REQUIRED): _____ **PHONE:** _____

Signature of Patient or Authorized Person (Required)

Signature: _____ **Date:** _____

If the patient signs and Do Not Attempt Resuscitation is checked in Section A, only the patient can revoke consent for the Do Not Resuscitate Order.

Print Name: _____

If patient lacks capacity, describe authority to consent on the patient's behalf: _____

If the patient has no Advance Directive, the following persons may consent for the patient in this order: Guardian, Spouse, Adult Children, Parents, Adult Siblings, Other Relative in descending order of blood relationship (Code of Virginia §54.1-2986)

FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED

www.virginiapost.org

patient label

29

NAME: _____ Date of Birth: _____

CARE SETTING WHERE POST WAS COMPLETED

☐ Long-Term Care ☐ Hospital ☐ Home ☐ Hospice Facility ☐ Outpatient Practice ☐ Other _____

Name of Care Setting: _____

Name of Healthcare Professional Preparing Form:

Print Name: _____ Date: _____ Organization: _____

This form is meant to reflect decisions for treatment based on the patient's current medical condition. It should be reviewed periodically and updated as needed with changes in condition, patient preferences, or setting.

Instructions for Use of This Form

Completing POST

- POST is not valid until signed by a physician, nurse practitioner or physician assistant who has a bona fide relationship with the patient. Nurse practitioners and physician assistants are authorized to sign POST forms under the Code of Virginia §54.1-2957.02 and §54.1-2952.2 respectively. Health care organizations may have policies that impose limitations on this authority based on the provider's individual scope of practice.
- Use of the original form is encouraged. A photocopy, fax or electronic version should be honored as if it were an original.

Using POST

- Patients may choose Full Interventions to authorize ventilation/intubation as a treatment for respiratory distress and still choose Do Not Attempt Resuscitation in the event of a full cardio-pulmonary arrest.
- When comfort cannot be achieved in the current setting, the patient, including someone who has chosen "Comfort Measures," should be transferred to a setting able to provide comfort (e.g. treatment of a hip fracture).
- Review POST periodically and update if needed with changes in condition, patient preferences or setting.

30

Revoking/Making Changes to Section A

- Administrative Code of Virginia §12VAC5-66-10 states "Durable DNR order shall also include a Physician Orders for Scope of Treatment (POST) form." Therefore, provisions under Code of Virginia §54.1-2987.1 apply to POST Section A.
- If "Do Not Attempt Resuscitation" is checked in Section A, and Section D is completed, and the patient has signed this form, no one has the authority to revoke consent for the DDNR order other than the patient as stated in the Code of Virginia §54.1-2987.1.
- If "Attempt Resuscitation" is checked in Section A, a legally authorized decision maker may make changes to carry out the patient's preferences in light of the patient's changing condition.

Making Changes to Sections B and C

- To change any orders in these sections, the current POST form must be voided and a new POST form completed.
- If the POST is revoked and no new POST form is completed, full treatment and resuscitation may be initiated.
- If a patient tells a healthcare professional that they wish to revoke their consent to POST or change POST, the healthcare professional caring for the patient should draw a line through the front of the form and write "VOID" on the original, date and sign, and notify the patient's physician. A new POST form then may be completed if desired by the patient.
- If not in a healthcare facility, the patient (or person authorized to make decisions on the patient's behalf, in keeping with the patient's goals for treatment) may revoke consent for POST orders by voiding the form as described above and informing a healthcare professional. The healthcare professional must then notify the patient's physician so that appropriate orders may be written and a new POST form created if desired by the patient.
- If the patient signs this form and becomes unable to make healthcare decisions, a legally authorized decision maker may continue carrying out the patient's preferences in light of the patient's changing condition, and in consultation with the treating physician, may sign, revoke consent to, or request changes to the POST orders (except in Section A as noted above).

FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED

POST forms are available to medical providers and organizations that have agreed to the standards set forth by the Virginia POST Collaborative. Contact: program.coordinator@virginiapost.org

Roadblock to Wide-Spread Use of POST Form Set in Virginia

31

- § 54.1-2987.1 of Virginia Code does not specifically mention POST and 12VAC5-66-10 of Administrative Code only *specifically* mentions POST in DNR section, but on POST form that is only Section A of a set of questions/orders. Remaining parts are not specifically about DNR
  - Writers of the Code section thought language was specific enough; however, legal counsel of some health care systems and hospitals have advised against using the POST form set
  - POST experts believe that an Opinion from Virginia's Attorney General that the Code language does apply to the POST form set, in full, would address the problem
    - If AG Opinion is that Code does not apply to POST, legislation to change the Code and, *perhaps*, an official memo from the Virginia Board of Health assuring/clarifying that the POST form set is recognized as a medical best practice for eliciting, documenting and honoring a patient's medical wishes are needed

Policy Options

32

Option 1: Take no action

Option 2: Introduce legislation to amend the Code of Virginia to include a Medical Aid-in-Dying statute that mirrors California's EOLOA statute, with the following additions: a. when informing patient of alternative to MAID, attending physician must include information about any possible treatments for the underlying disease, b. attending physician must attest that patient enrolled in hospice or was informed of EOL services , c. if patient is in nursing facility, one witness *may* be person designated by facility, d. adopt rules to facilitate collection of information regarding compliance, e. provide an online guidebook and establish training opportunities for medical community to learn about the MAID process and medications that may be used (NOTE: Language will be provided to members and placed on the JCHC website 5 business days prior to the November Decision Matrix meeting)

Option 3: By letter of the JCHC Chair, request that the Attorney General provide an opinion as to whether Virginia Code and regulation language regarding DDNRs and other orders regarding life-prolonging procedures applies to POST form sets, including parts A, B, C and D. If opinion is that language does not apply, also:

Option 3a: Introduce legislation to change the Code of Virginia (including Administrative Code) to insert "POST form set" into Virginia statute relating to orders regarding life-prolonging procedures

Option 3b: By letter of the JCHC Chair, request an official memo from the Virginia Board of Health assuring/clarifying that the POST form set is recognized as a medical best practice for eliciting, documenting and honoring a patient's medical wishes

33

Policy Options

Option 4: Introduce legislation to amend the Code of Virginia to require health regulatory boards of physicians, nurse practitioners, and physician assistants to promulgate regulations providing for the satisfaction of a one-time POST form set continuing education requirement of 0.5 – 1 hour for new licensure or re-licensure

Option 5: Place on the list of potential JCHC studies in 2019 a mini-study to obtain data, via a survey of health care systems and independent hospitals, on the degree to which these entities offer end-of-life planning. (For example, the number of Advanced Care Planning facilitators employed, if a patient indicates that he/she does not have an Advance Directive, does the entity have policy designed to guide staff on whether, and if so, how to discuss the topic with the individual, etc.)

Option 6: By letter of the JCHC Chair, request that the Virginia Department of Health consider the development of a unique POST registry that is accessible from various electronic medical records, allows electronic completion and is accessible in real-time by first responders (which is not the case with the current registry).

34

Public Comment Slide

Written public comments on the proposed policy options may be submitted to JCHC by close of business on September 19, 2018.

Comments may be submitted via:

- E-mail: jchcpubliccomments@jchc.virginia.gov (Please do not submit to staff email address, which creates potential for your comments to unintentionally be missed.)
- Fax: 804-786-5538
- Mail: Joint Commission on Health Care
  P.O. Box 1322
  Richmond, Virginia 23218

Comments will be provided to Commission members and summarized during the November 21st decision matrix meeting.

(Please Note: All public comments are subject to FOIA release of records)

35

Appendix

36

Ten Reasons to Oppose Physician-Assisted Suicide

Compiled by The Family Foundation of Virginia

1) The "Choice" of Physician-Assisted Suicide Is an Illusion.
Laws allowing it are ripe for abuse. For instance, once the lethal prescription is handed to the patient, there is no accountability of what takes place next. A third party (including someone who stands to benefit financially from the patient's death) could administer the drug to the patient without patient consent, even if the patient changed her mind and struggled against the overdose. Laws do not require consent at the time of death, only consent to obtain the lethal prescription - a distinction which can give someone other the patient the power to decide when death occurs. In reality, there is no protected "choice" as proponents claim.

2) Physician-Assisted Suicide Is Not A Private, Personal Act.
Doctor prescribed death involves more than the patient. It necessitates a host of participants, including a doctor, a pharmacist and the state. It's a public act that requires medicine, law and society approve a lethal prescription that crosses the line between caring and killing. Significant issues of conscience are implicated for all the parties directly or indirectly involved.

3) Acceptance of Physician-Assisted Suicide Sends the Message that Some Lives Are Not Worth Living.
Social acceptance of physician-assisted suicide tells elderly, disabled and dependent citizens that their lives are not valuable. Doctors who list death by assisted suicide among the medical options for a terminally or chronically ill patient communicate hopelessness, not compassion.

4) Physician-Assisted Suicide Creates Legal Opportunity for Hidden Elder Abuse.
Elder financial abuse is a documented fact, costing victims an estimated $2.6 billion each year and can serve as a catalyst for other types of elder abuse. Society-approved death puts elders at greater risk for abuse through include being coerced, pressured or even forced into suicide.

5) Doctor Prescribed Death Compounds the Discrimination Experienced by People with Disabilities.
Disability rights groups are some of the strongest voices against physician-assisted suicide based on the experience of their community. According to disability rights leader, John Kelly, "As people with disabilities, we are already on the front line of a broken, profit-driven health care system which will naturally see a below $100 prescription as a cheaper alternative to experimental [and life extending] drugs." What's to prevent a prescription from becoming the treatment of choice to offer terminally or chronically ill patients? Doctor prescribed death will always be the cheaper option.

37

Ten Reasons to Oppose Physician-Assisted Suicide, Cont'd

Compiled by The Family Foundation of Virginia

6) The Practice of Physician-Assisted Suicide Creates A Duty to Die.
Suicide is not medical care. Escalating health-care costs, coupled with a growing elderly population, set the stage for an American culture eager to embrace alternatives to expensive, long-term medical care. The so-called "right to die" may soon become the "duty to die" as our senior, disabled and depressed family members are pressured or coerced into ending their lives. At a time when health insurance coverage is in flux for millions of Americans, discussions of legalizing doctor-prescribed death seems especially dangerous. In a dollar-driven environment, it's too tempting for death to become a reasonable substitute to treatment and care when medical coverage is uncertain and medical costs continue to rise. In Oregon, at least two patients receiving medical care under the state-funded Oregon Health Plan report being denied chemotherapy but offered assisted suicide.

7) There Are Better Medical Alternatives.
Palliative Care specialist, Dr. Dan Maison, says, "One phrase that gets under my skin and breaks my heart is when someone says, 'Well, they told me there is nothing more they could do.' There's always more we can do." Regarding Brittany Maynard, ""Actually, we take care of folks like her all the time, and we're able to keep almost all of them very comfortable," he said.

8) The Practice of Physician-Assisted Suicide Threatens to Destroy the Delicate Trust Relationship Between Doctor and Patient.
Every day patients demonstrate their faith in the medical profession by taking medications and agreeing to treatment on the advice of their physicians. Patients trust that the physicians' actions are in their best interest with the goal of protecting life. Physician-assisted suicide endangers this trust relationship by making physicians actors in a patient's death.

9) The Foremost Purpose of the State Is to Protect Human Life.
This requires the state to proscribe acts that would intentionally and unjustifiably end human life. Personal autonomy, while an essential component of liberty, is not and cannot be absolute.

10) There Is a God, and He Alone Possesses the Authority to Determine When a Person's Life Begins and Ends.
Every human life is sacred because he or she was brought into existence by a transcendent Creator who, by virtue of His position as Creator, reserves the exclusive right to determine the moment that each life begins and ends. Therefore, we should seek to protect and preserve human life from conception to natural death. American jurisprudence, as well as Virginia's own Constitution, has always recognized that every person possesses certain rights bestowed upon them by their Creator, and that we also owe certain duties to that Creator. Section 16 of VA's Bill of Rights even declares that "it is the mutual duty of all to practice Christian forbearance, love, and charity towards each other."

38

Interim MAID Report

Medical Aid-in-Dying (MAID) Interim Report

Joint Commission on Health Care

August 22, 2017 Meeting

Michele Chesser, Ph.D., Executive Director

* I would like to thank Meagan D. Sok, JCHC Intern, for her work on this study

40

Study Mandate

- Delegate Kaye Kory requested via letter that the JCHC study the issue of Medical Aid-in-Dying (MAID). The delegate asked that the study include a review of states that currently authorize MAID and address the following questions:
  - What has been the impact of informing patients about end-of-life options such as hospice care and palliative care?
  - In current MAID states, how have the following acted to implement the law?
    - Health care providers
    - Health care systems
    - Health care institutions
  - In current MAID states, have people been coerced to ingest end-of-life medication?
    - Have any of the states enacted protections to discourage or prevent coercion?
  - Has the implementation of the law impacted any state's health care costs?
  - Using data from states that allow medical aid-in-dying, how many people would likely utilize medical aid-in-dying if it became law in Virginia?
- JCHC members approved the study during the Commission's May 23, 2017 work plan meeting

41

MAID Study Work Group

- A work group was created to discuss Medical Aid-in-Dying and consider components of the statute that will be one of the policy options
- Meeting 1: July 25, 2017
  - Overview of issue presented by Dr. Chesser
  - Discussion of MAID
- Meeting 2: August 25, 2017
  - Discussion of policy options and statute components
- Meeting 3: TBD
  - Discussion of statute components

42

MAID Study Work Group

- ALS Association
- American Cancer Society
- American Lung Association
- Anthem
- Bon Secours
- Capital Caring
- Carilion
- Compassion and Choices
- DARS
- DBHDS
- DHP
- DisAbility Law Center
- DMAS
- Family Foundation
- HCA Healthcare Virginia
- INOVA
- Mary Washington Healthcare
- Medical Society of Virginia
- NAMI
- Office of the Secretary of Health and Human Resources
- Riverside Health System
- Robert Misbin, MD
- Senior Navigator
- Sentara
- Social Worker, Diane Kane
- Society for Critical Care Medicine
- The Arc of Virginia
- University of Virginia
- Virginia Association of Health Plans
- Virginia Commonwealth University Health System
- VDH
- Virginia Association of Health Plans
- Virginia Association for Hospices and Palliative Care
- Virginia Catholic Conference
- Virginia Centers for Independent Living
- Virginia Health Care Association
- Virginia Hospital and Healthcare Association
- Virginia Nurses Association
- Virginia Public Access Project
- Virginia Society for Human Life
- Virginia Trial Lawyer Association

43

Definition of Medical Aid-in-Dying

- The ability of a patient to obtain a medication to end their life if they are competent, terminally ill, and over 18 years of age
- The ability of a physician to prescribe a medication that will allow a competent, terminally ill individual over the age of 18 to end their life
- Some individuals/organizations prefer to use terms like assisted suicide
  - However, different legal definition with implications if worded as such in Virginia statute

44

Current Virginia Statute

- **§ 8.01-622.1. Injunction against assisted suicide; damages; professional sanctions**.
- A. Any person who knowingly and intentionally, with the purpose of assisting another person to commit or attempt to commit suicide, (i) provides the physical means by which another person commits or attempts to commit suicide or (ii) participates in a physical act by which another person commits or attempts to commit suicide shall be liable for damages as provided in this section and may be enjoined from such acts.
- B. A cause of action for injunctive relief against any person who is reasonably expected to assist or attempt to assist a suicide may be maintained by any person who is the spouse, parent, child, sibling or guardian of, or a current or former licensed health care provider of, the person who would commit suicide; by an attorney for the Commonwealth with appropriate jurisdiction; or by the Attorney General. The injunction shall prevent the person from assisting any suicide in the Commonwealth.
- C. A spouse, parent, child or sibling of a person who commits or attempts to commit suicide may recover compensatory and punitive damages in a civil action from any person who provided the physical means for the suicide or attempted suicide or who participated in a physical act by which the other person committed or attempted to commit suicide.

Emphasis added

45

Current Virginia Statute, Continued

- **D. A licensed health care provider who assists or attempts to assist a suicide shall be considered to have engaged in unprofessional conduct for which his certificate or license to provide health care services in the Commonwealth shall be suspended or revoked by the licensing authority.**
- E. Nothing in this section shall be construed to limit or conflict with § 54.1-2971.01 or the Health Care Decisions Act (§ 54.1-2981 et seq.). This section shall not apply to a licensed health care provider who (i) administers, prescribes or dispenses medications or procedures to relieve another person's pain or discomfort and without intent to cause death, even if the medication or procedure may hasten or increase the risk of death, or (ii) withholds or withdraws life-prolonging procedures as defined in § 54.1-2982. This section shall not apply to any person who properly administers a legally prescribed medication without intent to cause death, even if the medication may hasten or increase the risk of death.
- F. For purposes of this section:
- "Licensed health care provider" means a physician, surgeon, podiatrist, osteopath, osteopathic physician and surgeon, physician assistant, nurse, dentist or pharmacist licensed under the laws of this Commonwealth.
- "Suicide" means the act or instance of taking one's own life voluntarily and intentionally.
- 1998, c. 624; 2015, c. 710.

Emphasis added

46

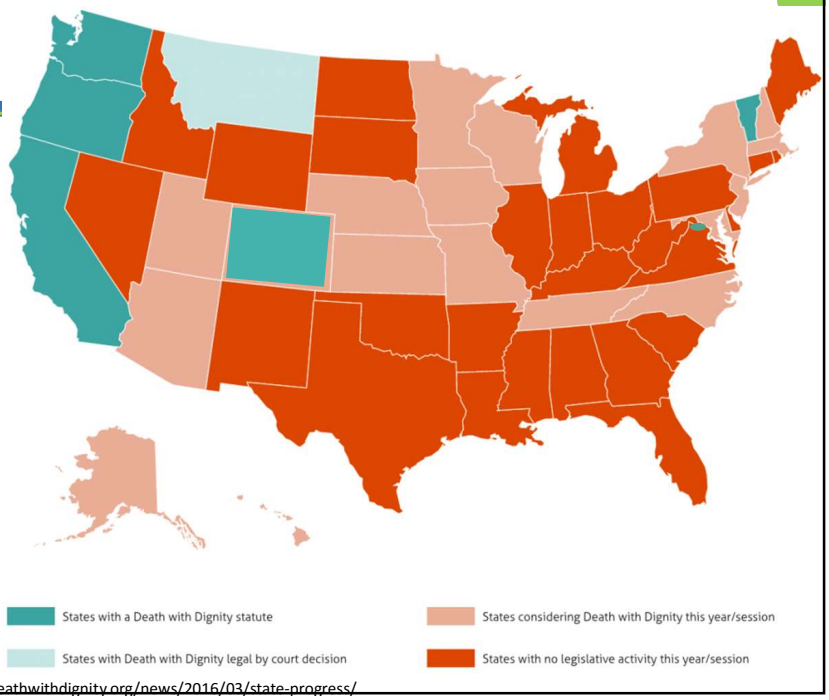
Existing Medical Aid-in-Dying Statutes

47

MAID: U.S. Landscape

States with MAID Laws:
Oregon (1998)
Washington (2008)
Vermont (2013)
California (2016)
Colorado (2016)
Washington, D.C. (2017)

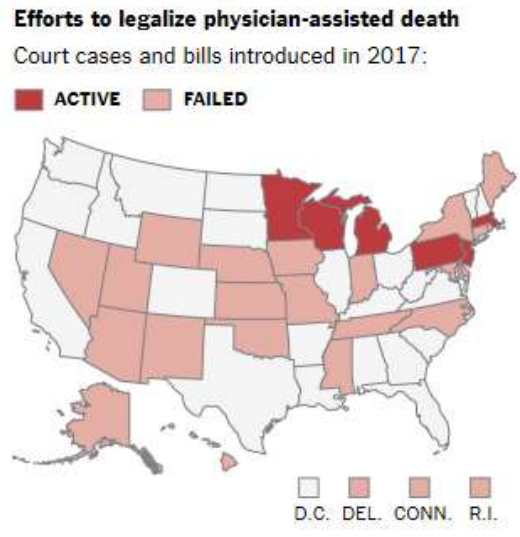
***By Judicial Review, legal in Montana (2009):**
Nothing in the state law prohibits MAID. Physicians cannot be prosecuted so long as the patient is competent, terminally ill, at least 18 years of age and acting voluntarily

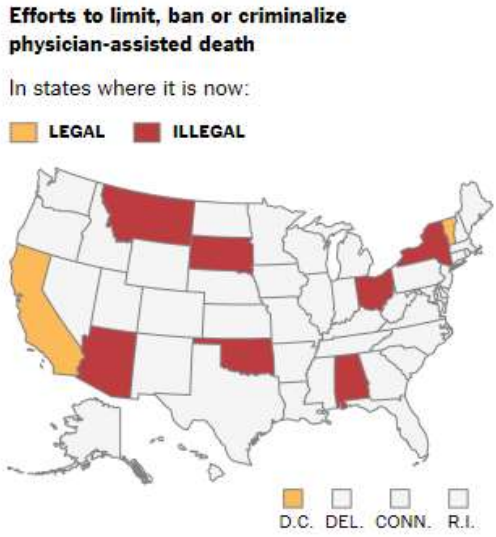


https://www.deathwithdignity.org/news/2016/03/state-progress/

48

2017 State Actions





Status of bills and court cases as of July 2017. Source: https://www.nytimes.com/2017/08/05/opinion/sunday/dying-doctors-palliative-medicine.html

49

Generally, Existing MAID Statutes Include:

Eligibility Criteria:

- Adult, 18 years of age and older
- Resident of the state
- Suffer from a terminal illness
- Able to self-administer the medication

Requires physician provide the following to the patient:

1. Diagnosis with prognosis
2. Range of options including palliative care and hospice care
3. Risks and probable death from prescription

Process:

- Attending and consulting physicians determine and agree that the patient suffers from a terminal disease with less than six months to live.
- Patient must provide 2 voluntary oral requests no less than 15 days apart.
- Patient must provide a signed written request (form provided) for the medication, co-signed by 2 witnesses
- Physician to provide prescription at least 15 days after the initial oral request and at least 48 hours after the signed request.
- Before providing the prescription, the physician must confirm the patient has not rescinded the request and remind the patient that the patient is not required to ingest the medication.
- If either physician believe the patient is suffering from depression or any behavioral health condition that may be impacting their choice, they are to refer the patient to a psychiatrist before proceeding.
- For prescription: After obtaining patient approval, attending physician calls pharmacy to alert pharmacist of the prescription to be filled and sends the written prescription through specified means.
- When ingesting, patient must self-administer the medication.

50

Oregon (1998 Statute)

- Eligibility: Oregon resident, determined by attending and consulting physician to have a terminal disease, and voluntarily expressed wish to die
- Consulting physician shall examine the patient and relevant medical records and confirm, in writing, the attending physician's diagnosis that the patient is suffering from a terminal disease, and verify that the patient is capable, is acting voluntarily and has made an informed decision.
- Counseling: If either physician believes the patient may have a mental health disorder (including depression) causing impaired judgement, the physician may refer the patient for counseling. Medication can only be prescribed if the counselor determines that the patient does not have impaired judgement resulting from a mental health condition
- Patient Request: Patient must provide two oral requests no less than 15 days apart, and a written request witnessed by two people
  - Prescription cannot be provided less than 15 days from initial oral request and less than 48 hours after written request

51

Oregon (1998 Statute) Continued (2)

- Witnesses: Must attest that to the best of their knowledge the patient is capable, acting voluntarily, and is not being coerced to sign the request. One of the witnesses shall be a person who is **not**:
  - A relative of the patient by blood, marriage or adoption;
  - A person who at the time the request is signed would be entitled to any portion of the estate of the qualified patient upon death under any will or by operation of law; or
  - An owner, operator or employee of a health care facility where the qualified patient is receiving medical treatment or is a resident.
- The patient's attending physician at the time the request is signed shall **not** be a witness
- If the patient is in a long term care facility at the time the written request is made, one of the witnesses shall be an individual designated by the facility and having the qualifications specified by the Department of Human Services

52

Oregon (1998 Statute) Continued (3)

- Informed Decision: The attending physician, to ensure that the patient is making an informed decision, shall inform the patient of:
  - His or her medical diagnosis and prognosis
  - The potential risks associated with taking the medication to be prescribed
  - The probable result of taking the medication to be prescribed
  - The feasible alternatives, including, but not limited to, comfort care, hospice care and pain control
- Immediately prior to writing the prescription for medication, the attending physician must verify that the patient is making an informed decision
- The attending physician also shall:
  - Recommend the patient notify next of kin
  - Counsel the patient about the importance of having another person present when the patient takes the medication and of not taking the medication in a public place (e.g. a hotel room, park)
  - Inform the patient that he or she has an opportunity to rescind the request at any time and in any manner, and offer the patient an opportunity to rescind at the end of the 15 day waiting period
  - Document all steps of the MAID process in the patient's medical record

53

Oregon (1998 Statute) Continued (4)

- Dispensing of Medication: The physician shall dispense medications directly if he/she is registered as a dispensing physician or, with the patient's consent, contact a pharmacist and inform the pharmacist of the prescription and deliver the written prescription personally or by mail to the pharmacist, who will dispense the medications to either the patient, the attending physician or an expressly identified agent of the patient
- Reporting Requirements: The physician shall fill-out and submit to the Center for Health Statistics required forms when medicine was prescribed (including the dispensing record) and after death. The Department of Human Services shall generate and make publically available an annual statistical report of de-identified, aggregate information.
- Liabilities: Fraud and coercion are a Class A Felony
- Effect on Construction of Wills, Contracts or Statutes:
  - No provision in a contract that would effect whether a person engages in MAID shall be valid.
  - The sale, procurement, issuance or rate of life, health, or accident insurance shall not be effected by MAID. In addition, ending one's life utilizing MAID shall not have an effect upon a life, health, or accident insurance or annuity policy.
  - Nothing in this statute shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing or active euthanasia. Actions taken in accordance with this statute shall not, for any purpose, constitute suicide, assisted suicide, mercy killing or homicide, under the law.

54

Oregon (1998 Statute) Continued (5)

- Immunities and Opting-Out: No one shall be punished for choosing to participate or not participate in MAID. Participation in MAID shall be voluntary. If a health care provider is unable or unwilling to carry out a patient's request the physician can transfer the patient to a new provider (which includes a new physician or new facility)
  - However, a provider (facility/health care system) may prohibit another provider (physician) from participating in MAID on the premises of the prohibiting provider if the prohibiting provider has notified the health care provider of the prohibiting provider's policy regarding participating in MAID. If the provider engages in MAID, he/she can receive sanctions within the context of the facility/health care system.
    - Suspension or termination of staff membership or privileges due to prohibited participation in MAID is not reportable under ORS 441.820 and shall not be the sole basis for a report of unprofessional or dishonorable conduct under ORS 677.415 (2) or (3)
  - A health care provider can participate in MAID while acting outside the course and scope of the provider's capacity as an employee or independent contractor; and a patient can contract with his or her attending physician and consulting physician to act outside the course and scope of the provider's capacity as an employee or independent contractor of the sanctioning health care provider.

55

Oregon (1998 Statute) Continued (6)

- Cause of death on death certificate is the terminal illness
- A request by a qualified individual to an attending physician to provide an aid-in-dying drug shall not provide the sole basis for the appointment of a guardian or conservator.
- Claims by governmental entity for costs incurred: Any governmental entity that incurs costs resulting from a person terminating his or her life in a public place shall have a claim against the estate of the person to recover such costs and reasonable attorney fees related to enforcing the claim

56

Statutes: What Other States Have Done Differently

- **Most states and D.C. used the Oregon statute as a blueprint**
- **CA:** The attending physician, consulting physician, or mental health specialist shall not be related to the individual by blood, marriage, registered domestic partnership, or adoption, or be entitled to a portion of the individual's estate upon death
- **VT:** Physician must inform the patient, *in writing*, of their diagnosis, prognosis, and range of treatment options including hospice and palliative care
- **DC:** Inform the patient of the availability of supportive counseling to address the range of possible psychological and emotional stress involved with the end stages of life
- **CO:** Attending physician must confirm no coercion or undue influence by having a private conversation with the patient
- **CA, CO:** As part of informed decision, physician must state the possibility that the patient may choose to obtain the medication but not take it.
- **VT, CA, CO**: Statute does NOT include the following: If the patient is in a long term care facility at the time the written request is made, one of the witnesses shall be an individual designated by the facility and having the qualifications specified by the Department of Human Services

57

Statutes: What Other States Have Done Differently

- **CA:** Attending physician shall give the patient the final attestation form, with the instruction that the form be filled out and executed by the patient within 48 hours prior to taking the medication
- **CA:** Not liable if a person assisted the patient by preparing the medication so long as the person did not assist with the ingestion of the drug
- **CA:** Instructs patient to keep the medication in a safe and secure location until the time that the qualified individual will ingest it
- **CA, WA, VT, CO:** Rules for safe disposal of unused medications
- **CA:** Actions taken in compliance with MAID statute shall not constitute neglect or elder abuse for any purpose of law
- **CO:** An individual utilizing MAID and on Medicaid shall not have their benefits denied or altered
- **CA:** Patient level data shall not be disclosed, discoverable, or compelled to be produced in any civil, criminal, administrative, or other proceeding
- **VT:** Does not require statistics to be collected for public use

58

Statutes: What Other States Have Done Differently

- **CA:** Prohibits an insurance carrier from providing any information in communications made to an individual about the availability of an aid-in-dying drug absent a request by the individual or his or her attending physician at the behest of the individual. The bill would also prohibit any communication from containing both the denial of treatment and information as to the availability of aid-in-dying drug coverage.
- **DC:** Death certificate states terminal disease as cause of death, but the Office of the Chief Medical Examiner shall review each death involving a qualified patient who ingests a covered medication and, if warranted by the review, may conduct an investigation.
- **DC:** Mayor shall issue rules to specify the recommended methods by which a patient may notify first responders of his or her intent to ingest a medication; and establish training opportunities for the medical community to learn about the use of covered medications by patients, including best practices for prescribing the medication.

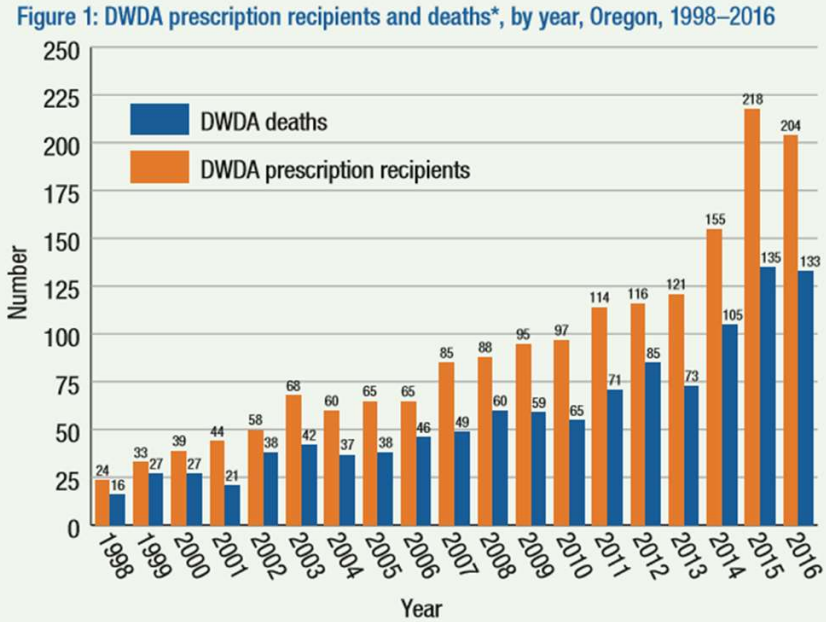
59

Current Data on MAID

Oregon, Washington and California statutes require that data be collected annually (as does D.C. and Colorado, but no data are available at this point)

Oregon MAID Utilization Rates

60

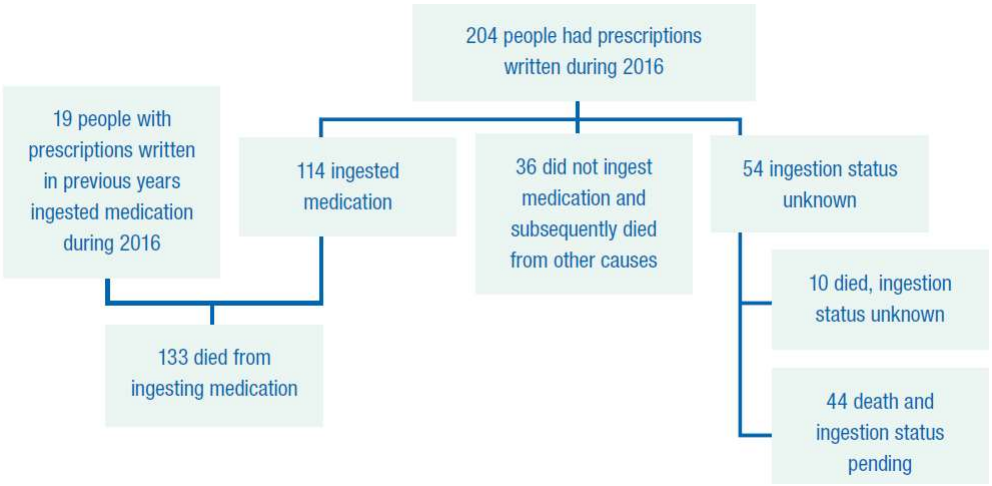


http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf

*As of January 23, 2017

61

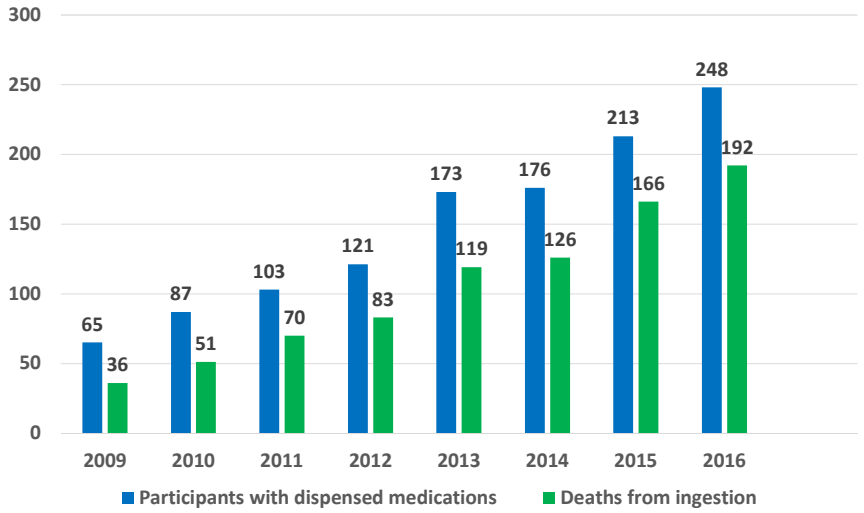
Summary of MAID Outcomes: Oregon, 2016



Source: Oregon DWDA 2016 Data Summary

62

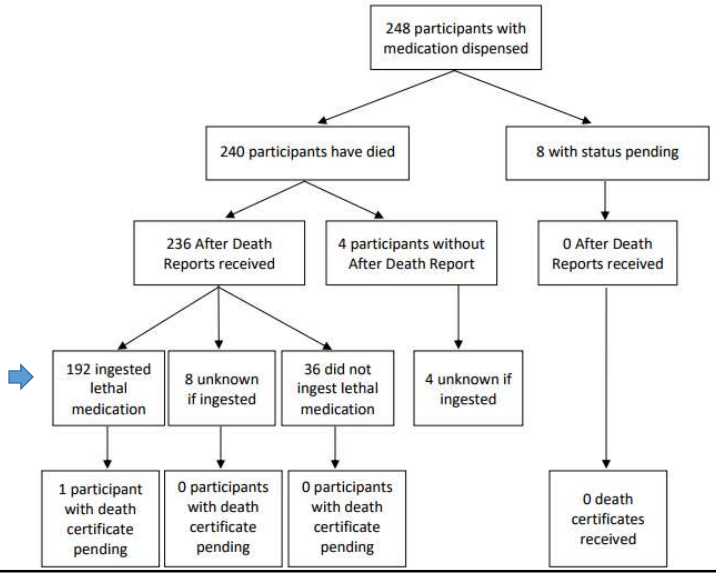
Washington MAID Utilization Rates



Data compiled from Washington's annual DWDA data reports, 2009-2016

63

Summary of MAID Outcomes: Washington, 2016

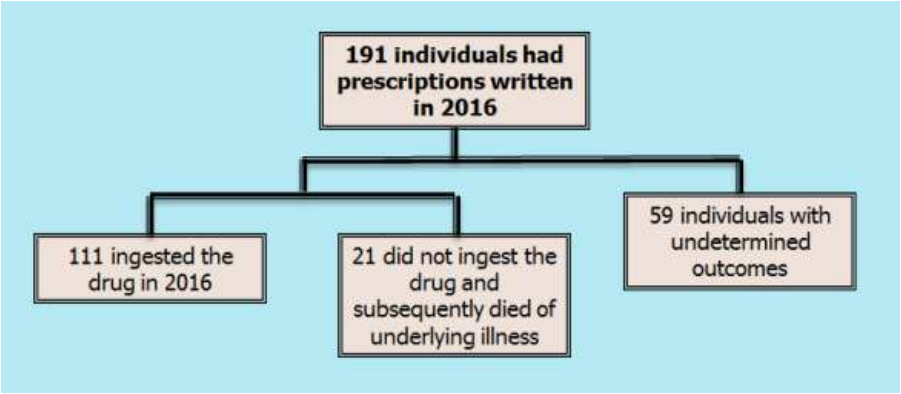


Source: http://www.doh.wa.gov/portals/1/Documents/Pubs/422109-DeathWithDignityAct2016.pdf

64

Summary of MAID Outcomes: California, 2016

258 individuals made a request for MAID to their physician



Note: California enacted MAID statute in 2016. As a result, all **data is for 6 months**, from June to December of 2016

Source: California EOLO Act 2016 Data Report

65

2016 MAID Demographics

Oregon: N=133 Washington: N=239 California: N=111 (In 6 months)

SEX (Male)

- Oregon: 72 (54.1%) Washington: 120 (50%) California: 51 (45.9%)

AGE

Oregon		Washington		California	
18-54	8 (6.1%)	18-44	6 (3%)	< 60	14 (12.6%)
55-64	18 (13.5%)	45-64	65 (27%)	60-79	55 (49.5%)
65-84	83 (62.4%)	65-84	126 (53%)	80-89	29 (26.1%)
85	24 (18%)	85	42 (18%)	90 or >	13 (11.7%)

Note: Age categories differ for each state

RACE / ETHNICITY

	Oregon	Washington	California
White	127 (96.2%)	232 (97%)	102 (89.5%)
Black	0	.	3 (2.6%)
Hispanic	2 (1.5%)	.	3 (2.6%)
Asian	2 (1.5%)	.	6 (5.3%)

Source: Each state's 2016 Data Summary/Report

66

2016 MAID Demographics

Oregon: N=133 Washington: N=239 California: N=111 (In 6 months)

Education

	OR	WA
Less Than High School	3.8%	4%
High School Graduate	17.4%	27%
Some College	28.8%	35%
Baccalaureate or Higher	50.0%	32%

	CA
No High School Diploma	5.4%
High School Diploma or GED	22.5%
Some College, No Degree	14.4%
Associate, Bachelor or Master Degree	45.9%
Doctorate or Professional Degree	11.7%

Marital Status

	OR	WA
Married	47.0%	43%
Widowed	19.7%	20%
Divorced	27.3%	27%
Domestic Partner	.	1%
Never Married/Single	6.1%	7%

Source: Each state's 2016 Data Summary/Report

67

2016 MAID Demographics

Insurance

Oregon: N=133 Washington: N=239 California: N=111 (In 6 months)

Oregon

Private	26.3%
Medicare, Medicaid or Other Gov't	61.7%
None	0.01%
Unknown	11.3%

Washington

Private Only	18%
Medicare, Medicaid Only	46%
Combo of Private & Medicare/Medicaid	17%
None	<1%
Unknown	6%
Other (Including VA)	11%

California

Private	18.9%
Medicare	44.2%
Medicaid	3.6%
Medicare/Medicaid (Dual Eligible)	9.0%
Medicare/Medicaid & Private Supplemental Insurance	11.7%
Has Insurance, but Type Unknown	9.0%
None	3.6%

Most private insurance pays for MAID medication and the physician visit
By law, federal funds cannot be used for MAID medication; therefore,
- Medicare and the VA cannot pay for MAID medication
  - Medicare enrollees may use their private supplemental insurance
- Medicaid can pay for MAID medication out of a pot of state-only funds

Source: Each state's 2016 Data Summary/Report

68

Underlying Illness, 2016

Oregon: N=133 Washington: N=239 California: N=111 (In 6 months)

Oregon

Cancer	78.9%
ALS	6.8%
Chronic Lower Respiratory Disease	1.5%
Heart Disease	6.8%
Other	6.0%

Washington

Cancer	77%
Neuro-degenerative Disease (including ALS)	8%
Respiratory Disease (including COPD)	8%
Heart Disease	6%
Other	2%

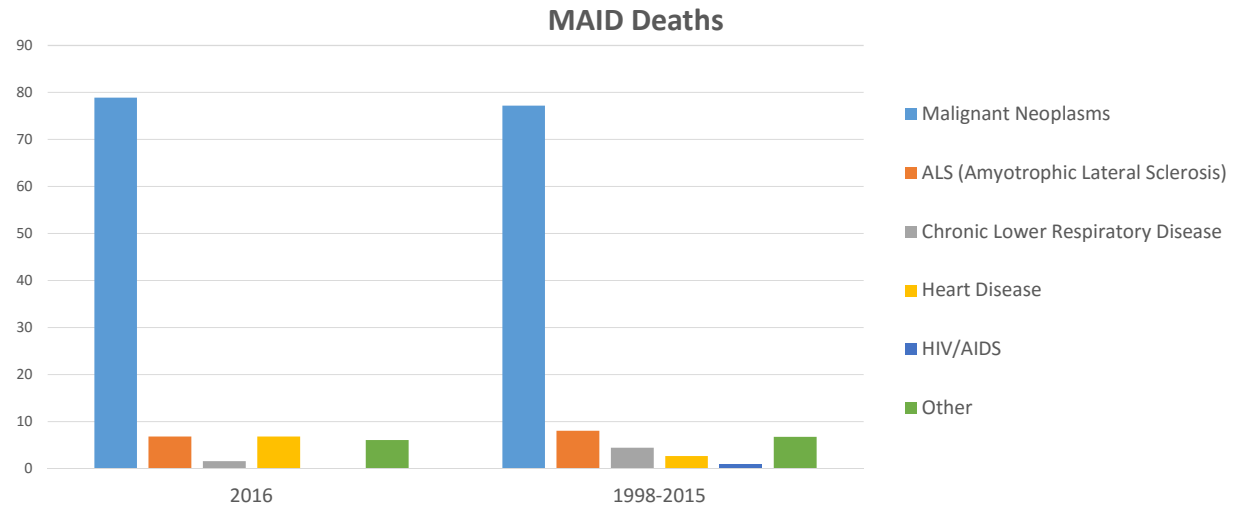
California

Cancer	58.6%
Neuromuscular	18%
Lung Respiratory Disease (non-cancer)	6.3%
Heart Disease	8.1%
Other	9%

Source: Each state's 2016 Data Summary/Report

69

Oregon: Underlying Illnesses (1998-2016)



Source: Oregon DWDA 2016 Data Summary

70

Circumstances When Medication Ingested or at Death, 2016

		OR	WA	CA
Location	Home	88.6%	88%	.
	LTC/ALF/ Adult Foster Care	6.8%	7%	.
	Hospital	2.3%	0	.
	Other	2.3%	2%	.
Hospice	Enrolled	88.7%	77%	83.8%
	Unknown	0	9%	4.5%

Oregon: N=133
Washington: N=239
California: N=111 (In 6 months)

Health Care Provider Present at Death (Oregon)

Prescribing physician	13 (9.8%)
Other provider	14 (10.5%)
No provider	102 (76.7%)
Unknown	4 (3.0%)

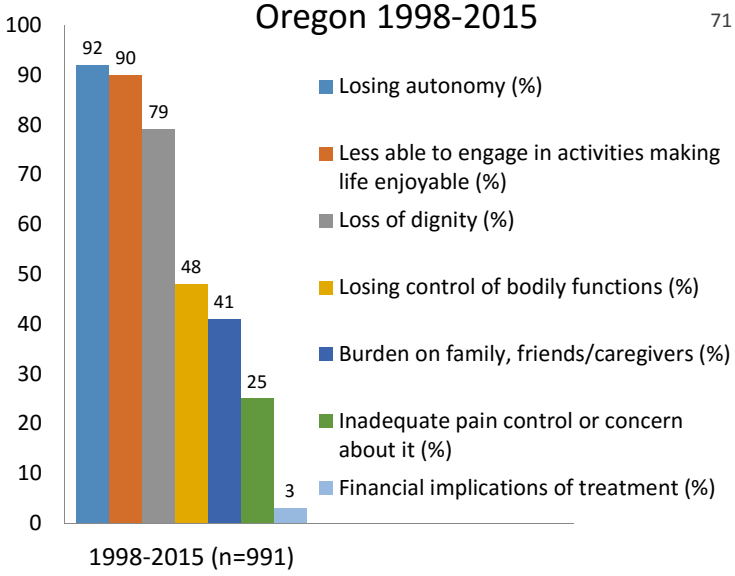
Source: Each state's 2016 Data Summary Report

MAID Patient Concerns

Oregon & Washington 2016

Reason Provided	OR %	WA %
Losing Autonomy	89.5	87
Unable to engage in enjoyable activities	89.5	84
Loss of dignity	65.4	66
Loss of bodily control	36.8	43
Burden on family	48.9	51
Concern about pain control	35.3	41
Financial implications of treatment	5.3	8

Oregon 1998-2015



Source: Oregon's and Washington's 2016 Data Summary/Report

What has been the impact of informing patients about end-of-life options such as hospice care and palliative care?

- In the states with available data (OR, WA, CA), the great majority of MAID users already were enrolled in hospice and had access to palliative care
  - Oregon: 88.7% (2016); 90.4% (1998-2015)
  - Washington: 77% (2016); 81% (2015); 69% (2014)
  - California: 83.8% (2016)
- All MAID statutes require that both the attending and consulting physician inform the patient about end-of-life options, including hospice and palliative care
- Hospice utilization has increased in Oregon since MAID was passed, but hospice utilization in Oregon has been among the highest in the nation since at least 1992[1]
- In Oregon, palliative care services spending and patient satisfaction have risen since 1998, when MAID became legal[2]
  - The request for information on MAID can lead to conversations between patients and their physicians about a range of end-of-life options[2]

1: Jackson A. The Inevitable—Death: Oregon's End-of-Life Choices. *Willamette Law Review*, Willamette University College of Law. Salem, Oregon, 45:1(137-160) Fall 2008; 2: Cain, Cindy L. Implementing Aid in Dying in California: Experiences from Other States Indicates Need for Strong Implementation Guidance. Los Angeles, CA: UCLA Center for Health Policy Research, 2016

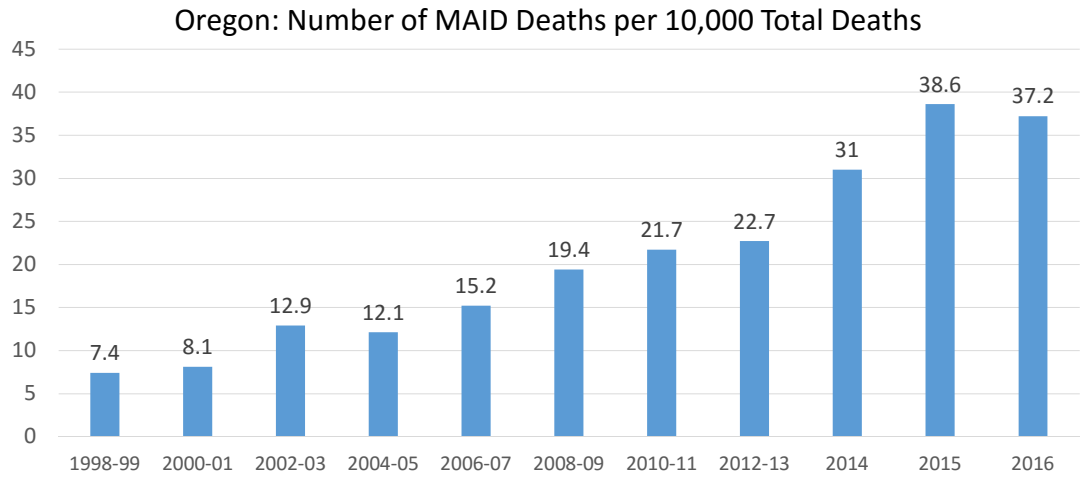
73

Coercion and Fraud

- Penalties for coercion and fraud included in statute:
  - Oregon: Class A felony
  - Washington: Class A felony
  - Vermont: Unable to find section on coercion/fraud
  - California: A felony
  - Colorado: Class 2 felony
  - D.C.: Class A felony
- Research on instances of coercion and/or fraud is ongoing and will be presented during the final presentation

74

Estimating MAID Utilization in Virginia



Data compiled from Oregon's annual DWDA data summaries, 1998-2016

75

Estimating MAID Utilization in Virginia

- In Oregon, there were 37.2 MAID deaths per 10,000 total deaths in 2016
  - Less than 1 percent of all deaths
- In California the death rate was 6.06 per 10,000 total deaths for the first six months after enactment (June-December, 2016)
  - Out of 191 prescriptions written, the outcome for 59 patients is still unknown
- For Oregon and Washington (states for which there is trend data), the number of people who died due to MAID medication has remained below 200 individuals
- Estimate for Virginia: Like Oregon and Washington, it is likely that the number of people requesting MAID would be quite small for the first few years, gradually increasing to approximately 242 individuals dying from MAID medications
  - Oregon: 37.2 / 10,000 = .00372 percent of all deaths
  - Virginia: .00372 x 65,000 (total deaths in 2015*) = 241.8

*Most recent data. Sources: Oregon, Washington and California data summaries/reports; and for Virginia death data: http://vaperforms.virginia.gov/indicators/healthfamily/mortalityLongevity.php

76

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77

References (in bold) and Bibliography

78

- **American Academy of Actuaries. (2017)**. End-of-life care in an aging world: A global perspective. *American Academy of Actuaries*, 1-10.
- Anguiano, L., et al. (2012). A Literature Review of Suicide in Cancer Patients. *Cancer Nursing, 35*(4), E14-E26.
- Balch, B. (2017). Death by lethal prescription: A right for older people or their duty? *Generations- Journal of the American Society on Aging, 41*(1), 42-46.
- Bharucha, A. J. et al. (2003). The pursuit of physician-assisted suicide role of psychiatric factors. *Journal of Palliative Medicine, 6*(6), 873-883.
- Blanke, C. et al. (2017). Characterizing 18 years of the Death with Dignity Act in Oregon. *JAMA Oncology, 243*, E1-E4.
- Breitbart, W. et al. (2000). Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA, 284*(22), 2907-2911.
- British Medical Association. (2016, January). *End-of-Life care and physician-assisted dying: 1. Setting the scene.* London: BMA House.
- British Medical Association. (2016). *End-of-Life care and physician-assisted dying: 2. Public dialogue research.* London: BMA House.
- **Cain, C. L. (2016)**. Implementing Aid in Dying in California: Experiences from Other States Indicates Need for Strong Implementation Guidance. Los Angeles, California: UCLA Center for Health Policy Research.
- Campbell, C. S., & Black, M. A. (2014). Dignity, death and dilemmas: A study of Washington hospices and physician-assisted death. *Journal of Pain and Symptom Management, 47*(1), 137-153.
- **Campbell, C. S., & Cox, J. C. (2012).** Hospice-assisted death? A study of Oregon hospices on Death with Dignity. *American Journal of Hospice & Palliative Medicine, 29*(3), 227-235.
- Chochinov, H. M. et al. (1995). Desire for death in the terminally ill. *Am J Psychiatry, 152*(8), 1185-1191.
- Clymin, J. et al. (2012). Washington state Death with Dignity Act. *Journal of Hospice & Palliative Nursing, 14*(2), 141-148.
- Craig, A. et al. (2007). Attitudes toward physician-assisted suicide among physicians in Vermont. *Journal of Medical Ethics, 33*(7), 400-403.

79

- Critser, S. E. (2018). National Standards and State Variation in Physician Orders for Life-Sustaining Treatment Forms. *JOURNAL OF PALLIATIVE MEDICINE, 21*(7), 978-986.
- **Dobscha, S. et, al. (2004).** Oregon Physicians' Responses to Requests for Assisted Suicide: A Qualitative Study. *Journal of Palliative Medicine, 7*(3), 451-461.
- Dore, M. K. (2010). "Death with Dignity": A recipe for elder abuse and homicide (Albeit not by name). *Marquette Elder's Advisor, 11*(2), 386-401.
- Drachsler, D. A. (2013, July 10). Suicide and the Law in Virginia. ACLU of Virginia. Retrieved from https://acluva.org/en/news/suicide-and-law-virginia
- Drum, C. E. et al. (2010). The Oregon Death with Dignity Act: Results of a literature review and naturalistic inquiry. *Disablity and Health Journal, 3*, 3-15.
- **Emanuel, E. J., & Battin, M. P. (1998).** What are the potential cost savings from legalizing physician-assisted suicide? *The New England Journal of Medicine, 339*(3), 167-172.
- Foley, H. H. (2008). Physician-assisted suicide in Oregon: a medical perspective. *Michigan law review*, 1613-1639.
- Fromme, E. et al. (2004). Increased family reports of distress or dying Oregonians 1996 to 2002. *Journal of Palliative Medicine, 7*(3), 431-442.
- Fulton, J. et al. (2018). Psychotherapy Targeting Depression and Anxiety for Use in Palliative Care: A Meta-Analysis. *Palliative Care Review, 21*(7), 1024-1037.
- **Ganzini. (2000, February 24).** Physicians' Experiences with Oregon Death With Dignity Act. *New England Journal of Medicine, 342*(8), 557-563.
- Ganzini, L., & Dobscha, S. K. (2003). If it isn't depression... *Journal of Palliative Medicine, 6*(6), 927-930.
- Ganzini, L. et al. (2001). Oregon physicians' attitudes about and experiences with end-of-life care since passage of the Oregon Death with Dignity Act. *JAMA, 285*(18), 2363-2369.
- Ganzini, L. et al. (2017). Physician's experiences with the Oregon Death with Dignity Act. *The New England Journal of Medicine, 342*(8), 557-563.

80

- Ganzini, L., Goy, E. R., & Dobscha, S. (2009, March 9). *Oregonians' reasons for requesting physician aid in dying*. Retrieved from Arch Intern Med: www.archinternmed.com
- Harkness, K. (2018, February 21). *Doctor: Insurance wouldn't pay for patients' treatments, but offered assisted suicide*. Retrieved from Daily Signal: http://dailysignal.com
- **Harman, S., & Magnus, D. (2017, July).** Early Experience with the California End of Life Act. *Health Care Policy and Law, 177*(7), 907-908.
- Hastings Center. (2018, January 4). Physician-Assisted Death: Ethical Debates, Professional Challenges, Societal Questions. Retrieved from https://www.thehastingscenter.org/category/end-of-life/
- Hedberg, K., & Tolle, S. (2009). Putting Oregon's Death with Dignity Act in perspective: Characteristics of decedents who did not participate. *The Journal of Clinical Ethics, 20*(2), 133-135.
- **Hickman, S., & Critser, R. (2018).** National Standards and State Variation iin Physician Orders for Life-Sustaining Treatment Forms. *Journal of Palliative Medicine, 21*(7), 978-986.
- Hudson, P. L. et al. (2006). Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: A systematic review. *Palliative Medicine, 20*, 693-701.
- **Jackson, A. (2008, Fall).** The Inevitable—Death: Oregon's End-of-Life Choices. *Willamette Law Review, 45*(1), 137-160.
- Kimbell, B. et al. (2015). Managing uncertainty in advanced liver disease: A qualitative mulitiperspective, serial interview study. *British Medical Journal*, 1-23.
- Kimbell, B. et al. (2016, July 18). *Embracing inherent uncertainty in advanced illness*. Retrieved from BMJ British Medical Journal: bmj.i3802
- Lee, B. C. (2014). Oregon's experience with aid in dying: findings from the death with dignity laboratory. *Annals of the New York Academy of Science, 0077*(8923), 1-7.
- LiPuma, S. H., & DeMarco, J. P. (2016). Palliative care and patient autonomy: Moving beyond prohibitions against hastening death. *Health Services Insights, 9*, 37-42.
- **Loggers, E. T. et al. (2013).** Implementing a death with dignity program at a comprehensive cancer center. *The New England Journal of Medicine, 368*(15), 1417-1424.

- Meghani, S. H., & Hinds, P. S. (2014, December 11). *Policy brief: The Institute of Medicine report Dying in America: Improving quality and honring individual preferences near the end of life*. Retrieved from Science Direct: www.science direct.com
- Miller, L. L. et al. (2004). Attitudes and experiences of Oregon hospice nurses and social workers regarding assisted suicide. *Palliative Medicine, 18*, 685-691.
- Monforte-Royo, C., Sales, J. P., & Balaguer, A. (2016). The wish to hasten death: Reflections from practice and research. *Nursing Ethics, 23*(5), 587-589.
- Mystakidou, K. et al. (2005, February 22). *Desire for death near the end of life: the role of depression, anxiety and pain*. Retrieved from Science Direct: www.sciencedirect.com
- **Nguyen, H. Q. et al. (2017, December 26).** Characterizing Kaiser Permanente Southern California's ExperienceWith the California End of Life Option Act in the First Year of Implementation: Research Letter. *Journal of American Medical Association Internal Medicine*, E1-E5.
- NIH National Cancer Institute. (2017, May 2). *Depression (PDQ)- Health Professional Version*. Retrieved from National Cancer Institute: https://www.cancer.gov
- **Norton, E. M., & Miller, P. J. (2012).** What their terms of living and dying might be: Hospice social workers discuss Oregon's Death with Dignity Act. *Journal of Social Work in End-of-Life & Palliative Care, 8*, 249-264.
- O'Connell, H. et al. (2004). Recent developments: Suicide in older people. *British Medical Journal, 329*, 895-899.
- O'Mahony, S. et al. (2005). Desire for hastened death, cancer pain and depression: Report of a longitudinal observational study. *Journal of Pain and Symptom Management, 29*(5), 446-457.
- **Orentlicher, D. et al. (2016).** Clinical criteria for physican aid in dying. *Journal of Pallative Medicine, 19*(3), 259-263.
- **Patients Right Council. (1998, January).** *Prescription death: Oregon struggles to implement new law*. Retrieved from Patients Right Council: http://patientsrightcouncil.org/site/update012

81

- Peled, H. et al. (2017). Enhancing informed consent for physician aid in dying: Potential role of handout on possible benefits of palliative care. *Journal of Oncology Practice, 13*(10), e838-e842.
- Pestinger, M. et al. (2015). The desire to hasten death: Using Grounded Theory for a better understanding "When perception of time tends to be a slippery slope". *Palliative Medicine, 29*(8), 711-719.
- Pope, T. M. (2017). Legal History of Medical Aid in Dying: Physician Assisted Death in the U.S. Courts and Legislatures. *New Mexico Law Review, forthcoming special symposium issue*.
- Rodin, G., et al. (2007). The desire for hastened death in patients with metastic cancer. *Journal of Pain and Symptom Management, 33*(6), 661-675.
- Rodriguez-Prat, A. et al. (2016, March 24). *Patient perspectives of dignity, autonomy, and control at the end of life: Systematic review and meta-ethnography*. Retrieved from Plos one: journal.pone.0151435
- Rogers, B. (2018, February 26). *Virginia earns a "B" on report card for access to palliative care*. Retrieved from VCHI Virginia Center for Health Innovation: http://innovatevirginia.org
- Rose, T. F. (2007). Physician-assisted suicide: development, status, and nursing perspectives. *journal of nursing law, 11*(3), 141-151.
- Rosenfeld, B. et al. (2014, March 28). *Does desire for hastened death change in terminally ill cancer patients?* Retrieved from Science Direct: www.elsevier.com/lcate/socscimed
- Russell, J. A., & Dulay, M. F. (2016). Hastened death in ALS. *Neurology, 87*, 1312-1313.
- Seattle Cancer Care Alliance. (2012). Death with Dignity. *Seattle Cancer Care Alliance*.
- Simon, R., Levenson, J., & Shuman, D. (2005). On Sound and Unsound Mind: The Role of Suicide in Tort and Insurance Litigation. *Journal of American Academy of Psychiatry Law, 33*(2), 176-182.
- Sinuff, T. et al. (2015). Improving end-of-life communication and decision making: The development of a conceptual framework and quality indicators. *Journal of Pain and Symptom Management, 49*(6), 1070-1080.

82

- Smith, K. A. et, al. (2015). Predictors of pursuit of physician-assisted death. *Journal of Pain and Symptom Management, 49*(3), 555-561.
- Stevinson, C. et, al. (2010). Defining priorities in prognostication research: results of a consensus workshop. *Palliative Medicine, 24*(5), 462-468.
- Sullivan, M. D., & Youngner, S. J. (1994). Depression, competence, and the right to refuse lifesaving medical treatment. *Am J Psychiatry, 151*(7).
- Voaklander, D. C. et al. (2017, August 30). *Medical illness, medication use and suicide in seniors: a population-based case-control study*. Retrieved from BMJ British Medical Journal: http://jech.bmj.com
- Waldrop, D. P. et al. (2018). Mediating Systems of Care: Emergency Calls to Long-Term Care Facilities at Life's End. *JOURNAL OF PALLIATIVE MEDICINE, 21*(7), 987-991.
- Waldrop, D., & Meeker, M. A. (2012, August 28). *Communication and advanced care planning in palliative and end-of-life care*. Retrieved from Science Direct: www.sciencedirect.com
- Waldrop, D., McGinley, J., & Clemency, B. (2018). Mediating systems of care: Emergency calls to long-term care facilities at life's end. *Journal of Palliative Medicine, 21*(7), 987-991.
- Wang, S.-Y. et al. (2015). Geographic variation of hospice use patterns at the end of life. *Journal of Palliative Medicine, 18*(9), 771-781.
- Wilson, K. et al. (200, Septemeber 11). *Attitudes of terminally ill patients toward euthanasia and physician-assisted suicide*. Retrieved from Arch Intern Med: www.archinternmed.com

83

84

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