Responding to Requests to Hasten Death in a NO-MAID State

Jennifer Moore Ballentine, MA David Nowels, MD, MPH Gregg VandeKieft, MD, MA



Objectives

- Describe MAiD laws, processes, patient profile
- Discern motivations for inquiring about hastening death
- Appropriately respond to requests to hasten death



Disclosures



No disclosures



Medical Aid Dying in the US





Palliative Care

Specialized medical care for people living with serious illnesses. It is focused on providing patients with relief from the symptoms and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.





Palliative Care

Provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.



Euthanasia

Physician or other clinician/ technician administers lethal dose of medication to relieve irremediable suffering.

In some countries*, legally allowed and regulated, requiring certain patient criteria and process steps



*Illegal in the U.S.

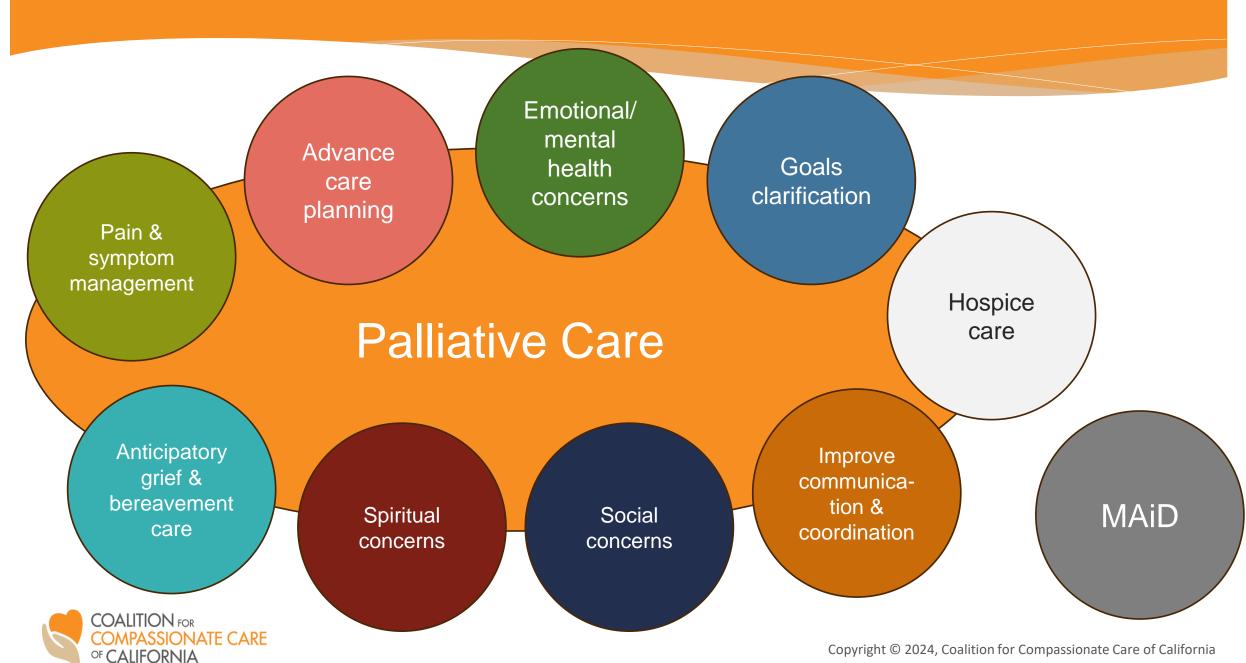




Medical Aid in Dying

Legally defined process by which a physician may prescribe a lethal dose of medications to a mentally capable patient with a terminal illness, to be self-administered at a time and place of the patient's choosing.





Terminology

- Physician-assisted suicide
- Physician-assisted death
- Physician aid in dying
- Aid in dying
- Self-directed death
- Self-deliverance
- "Death with dignity"
- Medical aid in dying
- Medically assisted dying





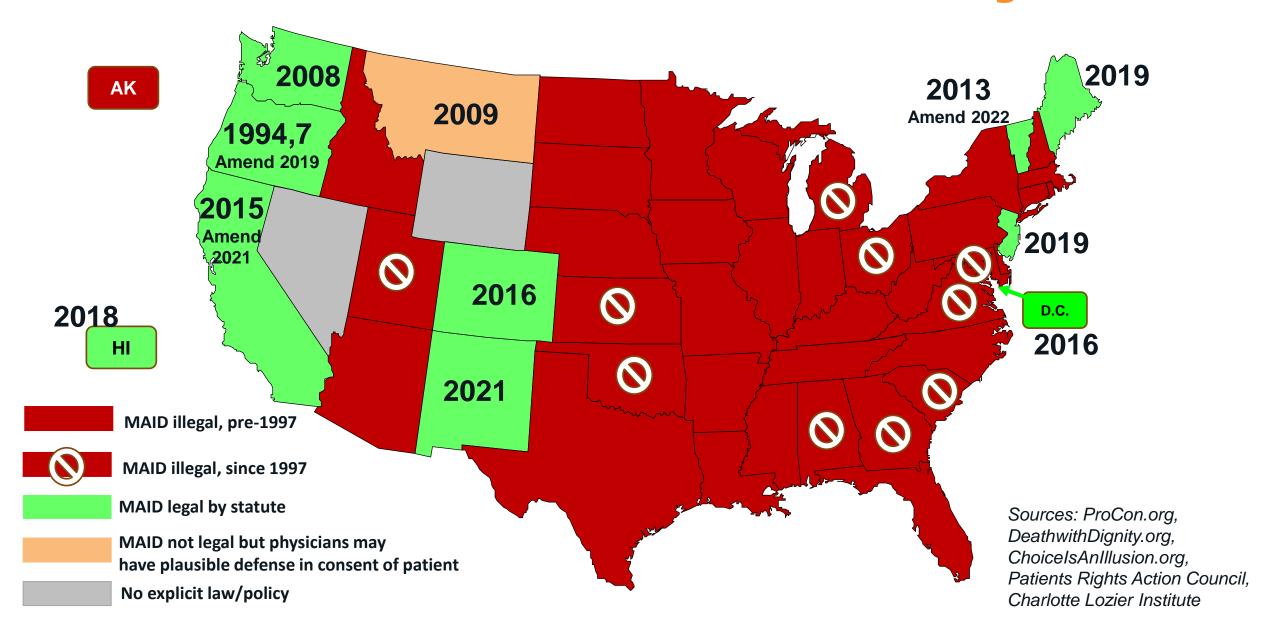
Terminology

- Physician-assisted suicide
- Physician-assisted death
- Physician aid in dying
- Aid in dying
- Self-directed death
- Self-deliverance
- "Death with dignity"
- Medical aid in dying
- Medically assisted dying

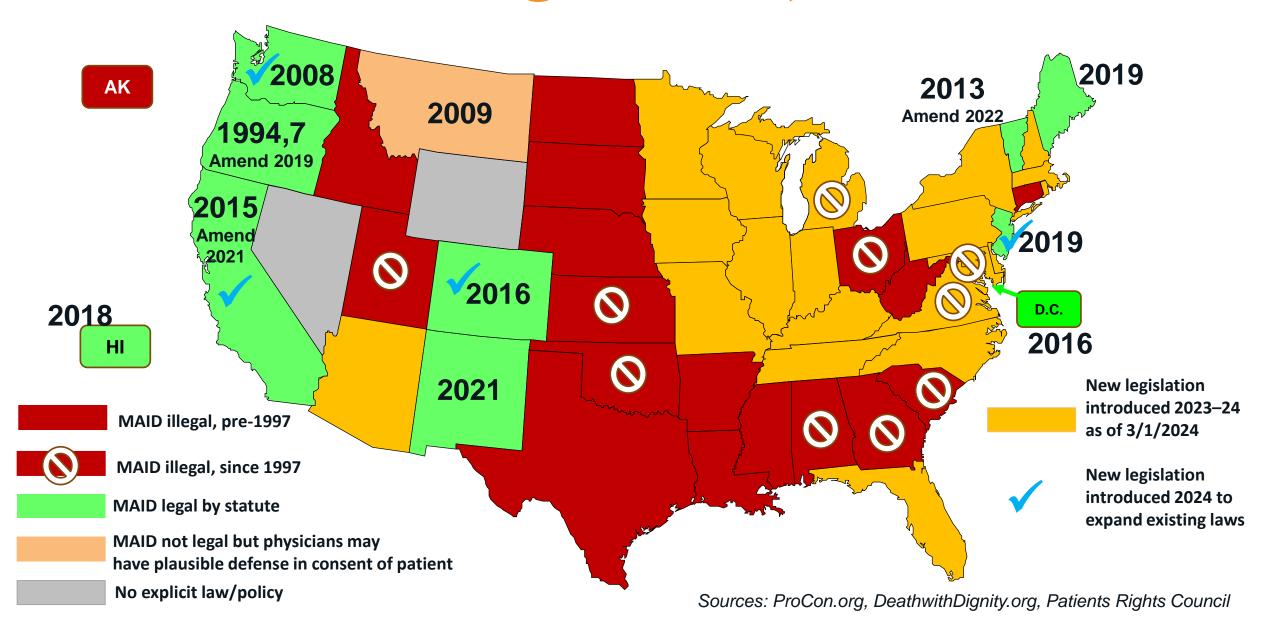




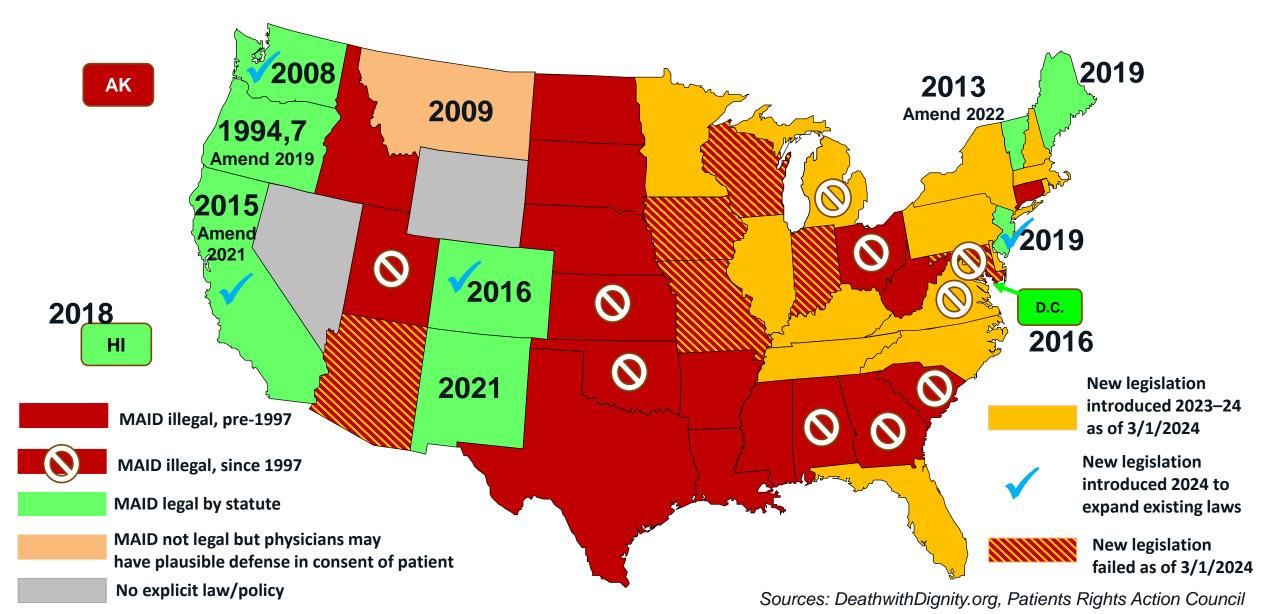
Status of MAiD Nationally



New Legislation, 2024



New Legislation, 2024



So What's the Big Deal?



PRO

- Compassion (Beneficence)
 - Role of medicine to relieve suffering
 - Limits of medical intervention
 - latrogenic harm
- Patient autonomy
 - Natural right to die
 - Recognition of "rational suicide"



So What's the Big Deal?

CON

- Risk of implicit or explicit coercion, exploitation (Justice)
 - "Option" may become "obligation"
- Contrary to the role of medicine, providers (Nonmaleficence)
 - Relieve patient of suffering, not life
 - Stall momentum for cures, interventions
 - Stall momentum for palliative care



Still a Big Deal

Favorable

Neutral

- AAHPM (2016)
- AAFP (2022)
- ANA (2019)
- APA (psychol; 2017)
- ASHP (2015)
- APhAssoc (2004)
- NASW (2004)

Opposed

- ACP (2017)
- AMA (2023)
- AMDA (1997)
- HPNA (2017*)
- IHPCA (2017)
- NHPCO (2021)

Roundup of U.S. medical & surgical society position statements:

Only 12 of 150 societies have any statement at all

(Barsness et al., 2020)

AMA Code of Ethics, 2023

- "It is understandable, though tragic, that some patients in extreme duress—such as those suffering from a terminal, painful, debilitating illness—may come to decide that death is preferable to life. However, permitting physicians to engage in assisted suicide would ultimately cause more harm than good.
- Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks."



MAID Process & Utilization



Common Process

- Patient:
 - 2 oral; 1 written requests
 - Written request witnessed
- Self-administer medications
 - Usually means ingest

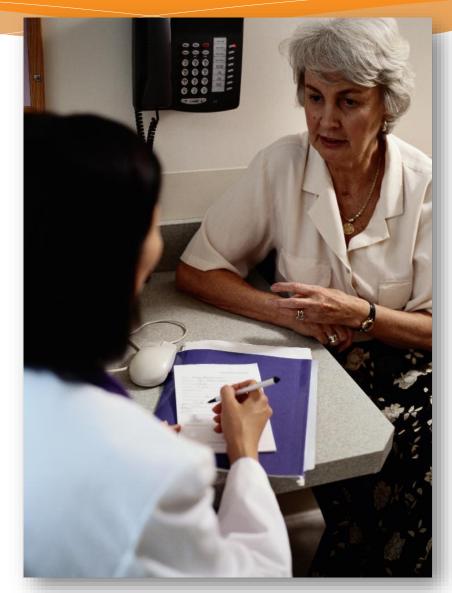
- Attending Physician (in NM & WA: MD, NP, PA):
 - Terminal diagnosis
 - 6 mos or less prognosis
 - Mental capacity
 - Inform of risks, alternatives
 - Prescribe or dispense meds
 - Report to state



Common Process

- Consulting Physician (in NM: must be MD):
 - Confirm diagnosis, prognosis, capacity
- Mental health consultant (req'd in HI):
 - Confirm capacity





Copyright © 2024, Coalition for Compassionate Care of California

If Process Followed

- For physicians/APPs:
 - No civil, criminal liability
 - No disciplinary actions, effect on employment
 - No sanction or penalty
 - Records can't be disclosed

- For patients:
 - No effect on admission, discharge, provision of care
 - No effect on life insurance, benefits
 - Death certificate lists terminal illness as COD



What Else?







Who Is Using MAiD, Where, and Why?



Who?

- 65+ yo
- Male
- White
- Not married
- Some college or higher education
- Cancer as terminal illness
- In hospice at TOD
- Has health insurance





Where?

At home





Reason for requesting	OR (1998–2022)	WA (2009–2022)
Loss of autonomy	90*	89
Less able to engage in activities that make life enjoyable	90	88
Loss of dignity	72	74
Burden on family, friends/caregivers	48	52
Loss of control of bodily functions	44	50
Inadequate pain control, or concern about it [†]	28	38
Financial implications of treatment	5	8

^{*}All percents rounded; †"or concern about it" only in OR

Reason for requesting	OR (1998–2022)	WA (2009–2022)
Loss of autonomy	90*	89
Less able to engage in activities that make life enjoyable	90	88
Loss of dignity	72	74
Burden on family, friends/caregivers	48	52
Loss of control of bodily functions	44	50
Inadequate pain control, or concern about it [†]	28	38
Financial implications of treatment	5	8
*All percents rounded: †"or concern about it" only in OR		

^{*}All percents rounded; †"or concern about it" only in OR

Reason for requesting	OR (1998–2022)	WA (2009–2022)
Loss of autonomy	90*	89
Less able to engage in activities that make life enjoyable	90	88
Loss of dignity	72	74
Burden on family, friends/caregivers	48	52
Loss of control of bodily functions	44	50
Inadequate pain control, or concern about it [†]	28	38
Financial implications of treatment	5	8
*All percents rounded: †"or concern about it" only in OR		

^{*}All percents rounded; †"or concern about it" only in OR

Reason for requesting	OR (1998–2022)	WA (2009–2022)
Loss of autonomy	90*	89
Less able to engage in activities that make life enjoyable	90	88
Loss of dignity	72	74
Burden on family, friends/caregivers	48	52
Loss of control of bodily functions	44	50
Inadequate pain control, or concern about it [†]	28	38
Financial implications of treatment	5	8

^{*}All percents rounded; †"or concern about it" only in OR

Mainly Existential Concerns

Quality of life
Meaning and purpose
Loss of personal intactness
and agency





Reason for requesting		OP 22)	WA (2009–2022)
Loss of autonomy	ALL REPORTED E	2V	89
Less able to enjoyable	ATTENDING		88
Loss c	PHYSICIAN AFTE		74
Burden on family	DEATH OF PATIEN	48	52
Loss of control		44	50
Inadequate pain contr	concern about it	28	38
Financial implications	of treatment	5	8

^{*}All percents rounded

Kaiser Permanente First Year Report

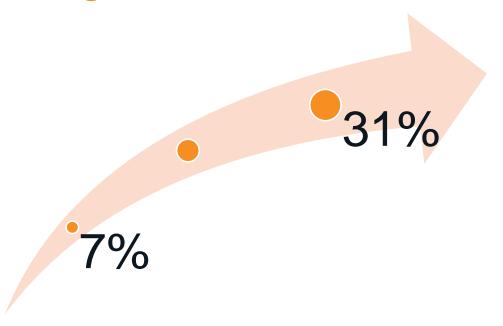
Patient Motivation	Rank in OR/WA
1. Suffering	n/a
2. Unable to enjoy daily activities	2
3. Inadequate pain control	6
4. Being a burden to family/friends	5
5. Loss of dignity	3
6. Loss of autonomy	1
7. Financial concerns	7



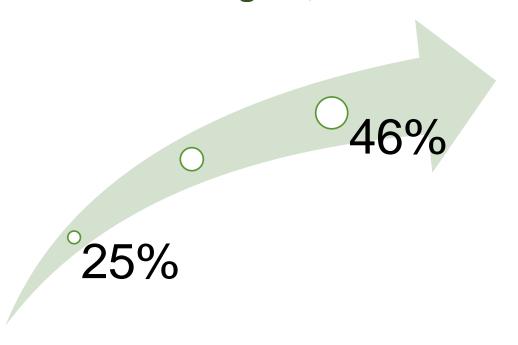
(Lawry, 2023; Nguyen et al., 2018)

"Inadequate Pain Control, or Concern About It"

Oregon, 1997 & 2022



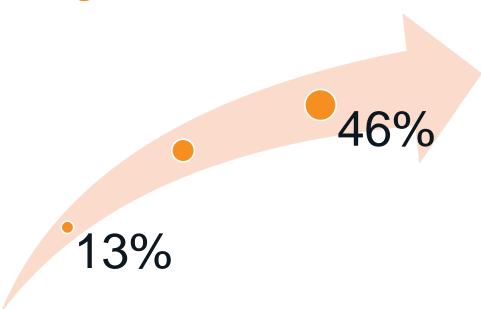
Washington, 2009 & 2022



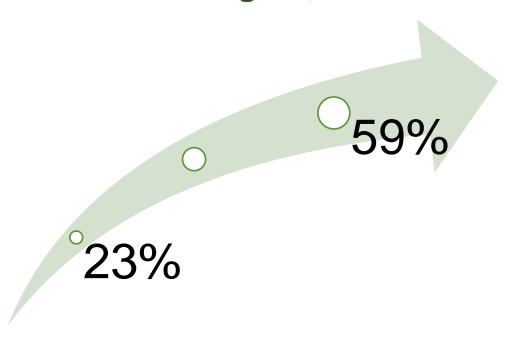


"Burden on Family/Caregivers"

Oregon, 1997 & 2022



Washington, 2009 & 2022

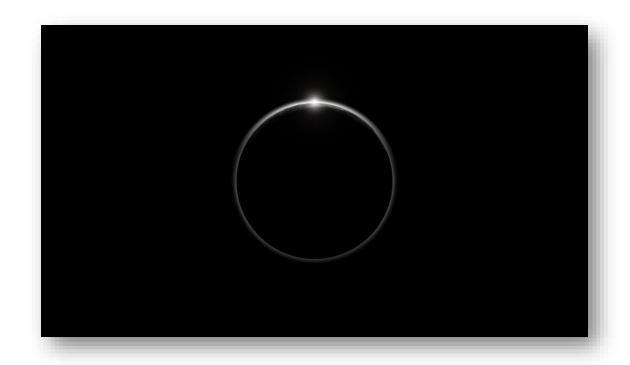




Not Uncommon Concerns!

"I don't mind dying . . . As long as I don't have to be there when it happens."

—Woody Allen







Some Clinicians' Experience

- "Just having discussion about MAiD opens the box to ask all ... questions."
- "I think it caught doctors' attention, and they said we have to be really aggressive with pain control and expand what we do to keep people comfortable...."
- "I felt a higher commitment ... so that she would not have to go through with it."
- "I felt like I was a failure."



Oregon Experience: Hospice RNs/SWs (Ganzini et al., 2002)

Some Clinicians' Experience

- "It opened my eyes more to my control issues, realizing I'm not in charge.... I was really not part of her decision. It was bigger than me."
- "He wasn't ... in a lot of pain.... And he wanted to die in a certain way. And he did it."
- "We need to look at that population [who desire control] and see if there's something we can do as well for them as we've done for people in pain."



Oregon Experience: Hospice RNs/SWs (Ganzini et al., 2002)

AMA Guidance

"Instead of engaging in assisted suicide, physicians must aggressively respond to the needs of patients at the end of life. Physicians:

- 1. Should not abandon a patient once it is determined that cure is impossible.
- 2. Must respect patient autonomy.
- 3. Must provide good communication and emotional support.
- 4. Must provide appropriate comfort care and adequate pain control."



Legalistic

- "I'm sorry, but even though I support you in this difficult time, I can't participate is assisting you with PAD."
- A "Just say No" approach misses all that we must say Yes to

Technical

 "So, to obtain the prescription, you must ..." followed by explanation of details of the law

Empathic

"I'm glad you asked me about this, but before I answer may I ask more about what led you to ask this question?"



- 1. Clarify the request
- 2. Understand the motivation
- 3. Affirm your commitment to care for the patient
- 4. Begin to address problems or concerns
- Discuss legal and ethical options

(Nowels, VandeKeift, & Ballentine, 2018)





"Jeanine" is 63

- COPD, O2 5 LPM
- Type 2 diabetes and hypertension
- Hospitalized 3x in past 8 mos.
- Reports severe fatigue, restricted lifestyle, loss of appetite, insomnia
- QOL poor and declining
- Spouse "exhausted," "doesn't get out much"; "Not the retirement we were hoping for"
- Worried about depleting finances
- "I'm just sick of being sick . . .
 Can't we just get this over with?"



CHECK YOURSELF **BEFORE YOU** WRECK YOURSELF

- 1. Clarify the request
- 2. Understand the motivation
- 3. Affirm your commitment to care for the patient
- 4. Begin to address problems or concerns
- Discuss legal and ethical options

- "Request" may be oblique
- Often not a request for death but request for help with living
- Paying attention, addressing concerns may ease or even extinguish request
- "Help me understand . . . "
- "Are you asking . . . "
- "How can I help . . . "



- 1. Clarify the request
- 2. Understand the motivation
- 3. Affirm your commitment to care for the patient
- 4. Begin to address problems or concerns
- Discuss legal and ethical options

- Typical timing: at diagnosis, when symptoms worsen, support decreases
- Look for recent change
- Listen/assess for pain, depression, hopelessness, fear
- "What's worst for you right now?"
- "What do you fear is coming?"
- "What will be better if . . ."
- "Do you feel depressed most of the time?"

 COALITION FOR COMPASSIONAL

- 1. Clarify the request
- 2. Understand the motivation
- 3. Affirm your commitment to care for the patient
- 4. Begin to address problems or concerns
- Discuss legal and ethical options

- Disease progression has effects across dimensions
- Isolation, diminished value as person
- Dismissing distress will only deepen it
- Clearly state intention to care
- "I will work with you to make your life the best it can be . . ."
- "Let's focus on a few things we can improve right now while we figure out long-term issues, too." COMPASSIONATE

- 1. Clarify the request
- 2. Understand the motivation
- 3. Affirm your commitment to care for the patient
- 4. Begin to address problems or concerns
- Discuss legal and ethical options

- Step up pain and symptom management as indicated
- Assess for suicidal ideation; if indicated, employ prevention techniques
- Manage expectations for outcomes;
 negotiate timeframes for reevaluation
- Address fears, existential concerns
- Obtain assistance from team members
- Assess caregiver burden; enhance support

- 1. Clarify the request
- 2. Understand the motivation
- 3. Affirm your commitment to care for the patient
- 4. Begin to address problems or concerns
- Discuss legal and ethical options

- Discontinuing burdensome therapies
- Palliative sedation if symptoms severe and intractable
- VSED



References

- American Medical Association. (2023). Opinion 5.7: Physician-assisted suicide. Retrieved 3/8/2024, https://code-medical-ethics.ama-assn.org/ethics-opinions/physician-assisted-suicide
- Barsness, J. G., Regnier, C. R., Hook, C. C., et al. (2020). US medical and surgical society position statements on physician-assisted suicide and euthanasia: A review. BMC Medical Ethics. 21, 111. https://doi.org/10.1186/s12910-020-00556-5
- California Department of Public Health. (2023). California End of Life Option Act 2022 data report.
 https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life%20_Option_Act_Report_2022_FINAL.pdf
- Center for Health and Environmental Data, Colorado Department of Public Health & Environment. (2023). Colorado End of Life Options Act, 2022 data summary, with 2017–2022 trends and totals.
 https://drive.google.com/file/d/1DLML5hCvII0Udvt0vCalCziN9g9Lhgf9/view
- Ganzini, L., Harvath, T. A., Jackson, A., Goy, E. R., Miller, L. L., & Delorit, M. A. (2002). Experiences of Oregon nurses and social workers with hospice patients who requested assistance with suicide. New England Journal of Medicine, 347, 582–588. https://www.nejm.org/doi/full/10.1056/nejmsa020562



References

- Lawry D. R. (2023). Rethinking medical aid in dying: What does it mean to 'do no harm'? *Journal of the Advanced Practitioner in Oncology, 14*(4), 307–316. https://doi.org/10.6004/jadpro.2023.14.4.5
- Nguyen, H. Q., Gelman, E. J., Bush, T. A., Lee, J. S., & Kanter, M. H. (2018). Characterizing Kaiser Permanente Southern California's experience with the California End of Life Option Act in the first year of implementation. *JAMA Internal Medicine*, 178(3), 417–421. doi 10.1001/jamainternmed.2017.7728
- Nowels, D., VandeKeift, G., & Ballentine, J. M. (2018). Curbside consultation: Medical aid in dying. *American Family Physician*, 97(5), 339–343. https://www.aafp.org/pubs/afp/issues/2018/0301/p339.pdf
- Oregon Health Authority. (2023). Oregon Death With Dignity Act 2022 data summary.
 https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITY
 ACT/Documents/year25.pdf
- Washington State Department of Health. (2023). 2022 Death With Dignity. Report to the Legislature.
 https://doh.wa.gov/sites/default/files/2023-10/422-109-DeathWithDignityAct2022.pdf

