Written Testimony of Kim Callinan, President & CEO,
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Regarding SB 443, In Support of the Maryland End of Life Option Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act)
Maryland Senate Judicial Proceedings Committee
February 8, 2024

Introduction

My name is Kim Callinan. I am a long-time Maryland voter, having lived in Greenbelt and then Kensington with my husband and two children for 25 years.

I am also the President & CEO of Compassion & Choices and the Compassion & Choices Action Network. We are the nation's oldest and largest national consumer-advocacy nonprofit organization, working to improve care and expand options at life's end. We advocate for legislation to improve the quality of care for terminally ill patients and affirm their right to determine their own medical treatment options as they near the end of life.

On behalf of hundreds of thousands of Maryland residents and supporters nationwide, the Compassion & Choices Action Network supports SB 443, the Maryland End of Life Option Act (The Honorable Elijah E. Cummings and the Honorable Shane E. Pendergrass Act).

What is Medical Aid in Dying?

Medical aid in dying refers to a practice in which a mentally capable, terminally ill adult may request from their medical provider a prescription for a medication that they can self-ingest to die peacefully if their suffering becomes unbearable. Today, more than one in five people have access to this end-of-life care option.

Ten states (Oregon, Washington, Vermont, California, Colorado, Hawaii, New Jersey, Maine, Montana, and New Mexico), and the District of Columbia have authorized the compassionate option. Seven of these jurisdictions have authorized this end-of-life care option since 2015. The legislation includes time-tested safeguards. Most notably, the dying person is in charge of the process from start to finish and must be able to self-ingest the medication. Two providers must confirm that the adult is mentally capable, has a medical prognosis of six months or less to live, and is not being coerced. There are also more than a dozen additional regulations. All of these regulations are in addition to the education, training, and oversight that govern the practice of medicine for any medical procedure.

Medical aid in dying is entirely optional -- for both the provider and the patient. Nobody is forced to participate, and the availability of the option brings people comfort during the very worst, the very last part of the dying process.

The Growing Movement

Public opinion polling from a variety of sources, both nationally and at the state level, demonstrates that the American public consistently supports medical aid in dying.

In Maryland, more than seven out of 10 voters (71%) support medical aid in dying, including majorities across the geographic, political, racial, and political spectrums, according to a 2023 poll by Gonzales Research & Media Services.[1] The support in Maryland mirrors the support at the national level.

In addition, voters are eight times "more likely" (51%) than "less likely" (6%) to vote for a candidate that sponsors or supports medical aid-in-dying legislation, according to a national survey conducted in 2021.[2]

A 2023 nationwide poll by Susquehanna Polling & Research reported that nearly eight out of 10 of U.S. residents (79%) who self-identify as having a disability agree that "medical aid in dying (MAID) should be legal for terminally ill, mentally capable adults who chose to self-ingest medication to die peacefully.[3] A 2021 nationwide poll by Susquehanna Polling & Research reported that 68% of voters support medical aid in dying as an end-of-life care option. Additionally, when respondents were asked if they want the option of medical aid in dying personally for themselves, 67% said yes.[4] Gallup's 2020 Values and Beliefs poll shows that a majority of respondents have consistently favored medical aid in dying since Gallup first asked about it in 1996.[5] 2018)[6]

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[1] Poll conducted from January 9th through January 14th, 2023. A total of 823 registered voters in Maryland were queried by live, person-to-person telephone interviews, including both landline and cell phone numbers. Accessed at: bit.ly/GonzalesPollMDEndOfLifeOptionsAct2023

[2] Nationwide Poll Shows Strong Support for Advance Care-Dementia Planning, Medical Aid in Dying. USA SURVEY OVERVIEW, NOV. 24, 2021. Accessed at: susquehannapolling.com/wp-content/uploads/2023/06/PollMemo-CandC-SPR-Nov-24-21.pdf

[3] USA/National Public Opinion Survey of 1,004 respondents - Cross Tabulation Report, February 2023. Accessed at: https://bit.ly/SPRNatDisabilityPoll2023

[4] *Nationwide Poll Shows Strong Support for Advance Care-Dementia Planning, Medical Aid in Dying*, Susquehanna Polling & Research, Omnibus Survey (2021). Available from: https://compassionandchoices.org/docs/default-source/default-document-library/usa-omnibus-cross-tabulation-report-final-november-2021-2.pdf?sfvrsn=74705b4b_1

[5] Prevalence of Living Wills in U.S. Up Slightly. Jones, Jeffrey (2020) Gallup. Available from: https://news.gallup.com/poll/312209/prevalence-living-wills-slightly.aspx

[6] Brenan, Megan, Americans' Strong Support for Euthanasia Persists, May 31, 2018. Available from: https://news.gallup.com/poll/235145/americans-strong-support-euthanasia-persists.aspx?g_source=link_NEWSV9&

Support for Medical Aid in Dying is Also Strong Within the Medical Community

Among U.S. physicians, support for medical aid in dying is also strong. A 2020 Medscape poll of 5,130 U.S. physicians from 30 specialties demonstrated a significant increase in support for medical aid in dying from 2010.[7] A 2021 Gynecologic Oncology survey showed 69% of respondents believed that medical aid in dying should be legalized, a 15 point increase from 2020, when 55% of oncologists believed it should be legalized.[8] A 2022 study of Colorado physicians noted "those who have participated in [medical aid in dying] largely report the experience to be emotionally fulfilling and professionally rewarding," despite barriers to offering the end-of-life care option.[9] And 55% of physicians surveyed endorse the idea of medical aid in dying, agreeing that "Physician-assisted death should be allowed for terminally ill patients."[10]

Additionally, a 2022 survey of nurses demonstrated that most nurses would care for a patient contemplating medical aid in dying (86%).[11] There is growing recognition within the medical profession that patients want, need, and deserve this compassionate option at the end of life, and this growing recognition is burgeoning into collaboration. As more jurisdictions authorize medical aid in dying, the medical community is coming together, and providers are sharing their experiences and fine-tuning their collaborative efforts to serve dying patients better.

A Solid Body of Evidence

When crafting medical aid-in-dying legislation, lawmakers no longer need to worry about hypothetical scenarios or anecdotal concerns. We have more than 25 years of data since Oregon first implemented its law in 1997 and years of experience from the ten other authorized jurisdictions, including annual statistical reports from nine jurisdictions. The most relevant data — namely, those relating to the traditional and more contemporary concerns that opponents of legalization have expressed — do not

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g_medium=NEWSFEED&g_campaign=item_&g_content=Americans%27%2520Strong%2520Support%2520for%2520Euthanasia%2520Persists

[7] Medscape Ethics Report 2020: Life, Death, and Pain, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain.pdf

[8] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

[9] Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. *Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey.* J Gen Intern Med. 2022 Oct;37(13):3310-3317. doi: 10.1007/s11606-021-07300-8. Epub 2022 Jan 11. PMID: 35018562; PMCID: PMC8751472.

[10] *Medscape Ethics Report 2020: Life, Death, and Pain*, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain.pdf

[11] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

support and, in fact, dispel the concerns of opponents."[12] None of the dire predictions that opponents raised have come to fruition. There has never been a single substantiated case of misuse or abuse of the laws. The evidence confirms that medical aid-in-dying laws protect patients while offering a much-needed compassionate option. Public health departments in nine authorized jurisdictions have issued reports regarding the use of medical aid-in-dying laws: Oregon,[13] Washington,[14] Vermont,[15] California,[16] Colorado,[17] Hawai'i,[18] the District of Columbia,[19] Maine,[20] and New Jersey.[21] The following data from those jurisdictions addresses the most common inaccurate claims about medical aid in dying and sets the record straight. More detailed reports can be provided upon request.

- Cumulatively, for the past 25+ years, across all jurisdictions, just 8,729 people have taken the prescription to end their suffering.[22]
- Up to 37% of people who go through the process and obtain the prescription may never take it. This group consists of people who die from their underlying illness, another cause of death, or an unreported cause of death.[23] Even those who don't take the medication derive peace of mind simply from knowing they have the option if their suffering becomes too great.

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[12] *A History of the Law of Assisted Dying in the United States.* SMU Law Review, A. Meisel, (2019) Available from: https://scholar.smu.edu/cgi/viewcontent.cgi?article=4837&context=smulr

[13] *Oregon Death with Dignity Act Annual Reports* (1998-2022) Available from: https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx

[14] *Washington Death with Dignity Data* (2009-2022). Available from: https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData

[15] *Vermont Report Concerning Patient Choice at the End of Life.* (2018-2022) Available from: https://www.healthvermont.gov/systems/end-of-life-decisions/patient-choice-and-control-end-life.

[16] *California End of Life Option Act Annual Report* (2016-2022) Available from: https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx

[17] *Colorado End of Life Options Act Annual Report* (2017-2022) Available from: https://www.colorado.gov/pacific/cdphe/medical-aid-dying

[18] *Hawai'i Our Care, Our Choice Act Annual Report* (2019-2022) Available from: https://health.hawaii.gov/opppd/ococ/

[19] *District of Columbia Death with Dignity Act Annual Report. (*2017-2022) Available from: https://dchealth.dc.gov/publication/death-dignity-annual-reports

[20] *Maine Patient Directed Care at End Of Life Annual Report.* (2019-2022) Available from: https://www.maine.gov/dhhs/data-reports/reports

[21] *New Jersey Medical Aid in Dying for the Terminally Ill Act Data Summary* (2019-2022) Available from: https://nj.gov/health/advancedirective/maid/

[22] By compiling the data from each authorized jurisdiction's annual reports and aggregating that over all years, we arrived at these numbers. Medical Aid-in-Dying Utilization Report (2024) Available from: https://www.compassionandchoices.org/docs/default-source/default-document-library/final_maid-utilization-report_1-24-2024.pdf?sfvrsn=5a81525d_6

[23] *Id.*

- Fewer than 1% of the people who die in each jurisdiction use the law annually.[24]
- The majority of terminally ill people who use medical aid in dying — more than 87% — received hospice services at the time of their deaths.
- There is nearly equal utilization of medical aid in dying among men and women. There is no data on the utilization of medical aid in dying by non-binary people.
- Terminal cancer accounts for the vast majority of qualifying diagnoses, with neurodegenerative diseases such as ALS or Huntington's Disease following as the second leading diagnosis.
- Just over 90% of people who use medical aid in dying die at home.[25] According to various studies, most Americans would prefer to die at home.[26]

Medical Aid in Dying Protects Patients

The evidence is clear: medical aid-in-dying laws protect terminally ill individuals while giving them a compassionate option to die peacefully and ensuring appropriate legal protection for the care providers who practice this patient-driven option. SB 443 contains the same time-tested, evidence-based safeguards that have protected patients in other authorized jurisdictions.

There have been no documented or substantiated incidents of abuse or coercion across the authorized jurisdictions since Oregon implemented the first medical aid-in-dying law on Oct. 27, 1997. A 2015 report from the Journal of the American Academy of Psychiatry and Law noted, “There appears to be no evidence to support the fear that assisted suicide [medical aid in dying] disproportionately affects vulnerable populations.” [27] Vulnerable groups included the “elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people

[24] According to the Center for Disease Control, in 2019 in jurisdictions that authorized medical aid in dying, 427,296 people died in total. In 2019, authorized jurisdictions report 1,027 people died after being provided with a prescription for medical aid in dying–less than 0.002% of all total deaths in 2019. Center for Disease Control, *Deaths: Final Data for 2019*, July 26, 2021. Available from: https://stacks.cdc.gov/view/cdc/106058/cdc_106058_DS1.pdf

[25] By compiling the data from each authorized jurisdiction’s annual reports and aggregating that over all years, we arrived at these numbers. Medical Aid-in-Dying Utilization Report (2024) Available from: https://www.compassionandchoices.org/docs/default-source/default-document-library/final_maid-utilization-report_1-24-2024.pdf?sfvrsn=5a81525d_6

[26] Kaiser Family Foundation, Views and Experiences with End-of-Life Medical Care in the U.S., April 27, 2017. Available from: https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings/

[27] Gopal, AA. 2015. Physician-Assisted Suicide: Considering the Evidence, Existential Distress, and an Emerging Role for Psychiatry. Journal of the American Academy of Psychiatry and the Law. Vol 43(2): 183-190. Available from: http://jaapl.org/content/43/2/183

with psychiatric illnesses, including depression, or racial or ethnic minorities, compared with background populations."[28]

For Some, Comfort Care and Pain Management Is Not Enough

The vast majority of individuals who use medical aid in dying are also receiving hospice and palliative care, but they still want the option of medical aid in dying for a variety of reasons.[29] In other words, good hospice services and palliative care do not eliminate the need for medical aid in dying as an end-of-life care option. Breakthrough pain — severe pain that occurs even when a patient is already medicated — remains a nightmare experience for too many. In the National Breakthrough Pain Study, among respondents who had cancer (at all stages), 83.3% reported breakthrough pain. For those cancer patients who experienced breakthrough pain, only 24.1% reported that using some form of pain management worked every time.[30]

What we hear directly from terminally ill individuals is that people decide to use the law for multiple reasons all at once: pain and other symptoms such as breathlessness and nausea, loss of autonomy, and loss of dignity. It is not any one reason, but rather the totality of what happens to one's body at the very end of life. For some people, the side effects of treatments such as chemotherapy or pain medication (sedation, relentless nausea, crushing fatigue, obstructed bowels, to name a few), are just as bad as the agonizing symptoms of the disease. Others want the option of medical aid in dying because they want to try that one last, long-shot treatment with the peace of mind of knowing that if it results in unbearable suffering, they have an option to die peacefully.

Only the dying person can determine how much pain and suffering is too much. This law puts the decision in the hands of the dying person, in consultation with their doctor and loved ones, as it should be for such deeply personal healthcare decisions.

In Conclusion

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[28] Margaret P Battin, Agnes van der Heide, Linda Ganzini, Gerrit van der Wal, Bregje D Onwuteaka-Philipsen. Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. Journal of Medical Ethics, Volume 33, Issue 10, 2007. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2652799/

[29] By compiling the data from each authorized jurisdiction's annual reports and aggregating that over all years, we arrived at these numbers. Medical Aid-in-Dying Utilization Report (2024) Available from: https://www.compassionandchoices.org/docs/default-source/default-document-library/final_maid-utilization-report_1-24-2024.pdf?sfvrsn=5a81525d_6

[30] *Impact of breakthrough pain on community-dwelling cancer patients: results from the National Breakthrough Pain Study.* Katz, N.P, Gajria, K.L, Shillington, A.C., et. al. (2016). Postgraduate Medicine, 129(1), 32-39. Available from: https://pubmed.ncbi.nlm.nih.gov/27846789/

Authorizing the full range of end-of-life options, including medical aid in dying, allows people to engage in open conversations with their healthcare providers, their loved ones, and their faith leaders about their physical and spiritual needs at the end of life. Without the authorization of medical aid in dying, people nearing the end of life are unable to die in Maryland in the manner of their choosing, which for most is at home, surrounded by their loved ones.

We have over 25 years of experience since the first such law was enacted in Oregon, demonstrating that medical aid-in-dying laws provide an additional end-of-life option for many constituents while also protecting patients and providers. Allowing this legislation to become law brings peace of mind to terminally ill people at or near the end of their lives and their community. Furthermore, the cost of inaction is high.

Terminally ill people:

- May not try that one last miracle treatment out of fear it will be too painful.
- Need the peace of mind that having access to the full range of end-of-life options provides.
- Could experience needless suffering when they die, while families and healthcare providers remain powerless with no legal way to respond to pleas for help.

Furthermore, society also fails to gain from the benefits of medical aid in dying implementation, including:

- Better palliative care training.[31]
- Better hospice usage.[32]
- More open conversations and essential planning for the end of life.[33]

Maryland can realize these benefits for terminally ill people and their families right now by joining the growing number of jurisdictions that authorize this end-of-life option.

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[31] Singer, J., Daum, C., Evans, A., Schneider, S., Vugrin, M., & Loggers, E. (2023). An examination and proposed theoretical model of risk and protective factors for bereavement outcomes for family members of individuals who engaged in medical aid in dying: A systematic review. Palliative medicine, 37(7), 947–958. https://doi.org/10.1177/02692163231172242

[32] *Geographic Variation of Hospice Use Patterns at the End of Life.* Journal of Palliative Medicine, S.Y. Wang, M.D, Aldridge, C.P. Gross, et al. (2015). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696438/

[33] *Id.*

The debate quite simply comes down to who decides and who is in a better position to determine the care a patient receives at the end of life: the terminally ill patient in consultation with their provider and loved ones or the government.

We urge you to review the evidence, experience, data, and strong public support for this end-of-life care option to guide your policymaking. Thank you again, Chair and Members of the Committee, for your leadership on this important issue.

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The Compassion & Choices family comprises two organizations: Compassion & Choices (the 501(c)(3)), whose focus is expanding access, public education and litigation; and Compassion & Choices Action Network (the 501(c)(4)), whose focus is legislative work at the federal and state levels.

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