



Care and Choice at the End of Life

Joint Commission on Health Care (JCHC)
Chair, Senator Rosalyn R. Dance
Vice Chair Delegate T. Scott Garrett
P.O. Box 1322
Richmond, Virginia 23218

September 28, 2018

Re: Medical Aid in Dying Final Report; Support for Option 2, to introduce legislation to authorize medical aid in dying

Dear: Senator Dance and Delegate Garrett:

We appreciate the opportunity to provide comment on the recommendations presented during the public report on medical aid in dying and the subsequent recommendations delivered on September 18, 2018.

Compassion & Choices is the nation's oldest and largest nonprofit organization working to improve care and expand options at the end of life. We advocate for legislation to improve the quality of end-of-life care and which affirms an individual's right to determine their own medical treatment options as they near the end of life. As such, we are in support of option 2, to advance legislation to explicitly authorize medical aid in dying in the state of Virginia.

Multiple studies and the experience of hundreds of physicians, terminally ill patients and their families demonstrate that authorizing medical aid in dying not only expands options, but improves care at the end of life in a variety of ways including:

- Providing significant peace of mind to residents of the state, simply knowing the option is available;
- Prompting physicians to improve their knowledge about end-of-life care;
- Prompting in-depth conversations between physicians and their patients about the full range of end-of-life care options; and,
- Promoting more appropriate use of hospice and palliative care, growing these systems stronger.

In support of option 2, Compassion & Choices recognizes that all of the laws, including California's End of Life Option Act, are modeled after the Oregon Death with Dignity Act. Although the regulatory and procedural requirements vary slightly, each includes the same strict eligibility criteria as well as guidelines that meet the highest standard of care. We highly



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recommend that any legislative body considering a bill to authorize medical aid in dying take the opportunity to refine the language based upon the cumulative experience of the authorized states.

We generally support this style of bill, however we do have some concerns about the JCHC recommendation to include several of the provisions from the California law. In the third year of implementation, we know that many of the added regulatory requirements, particularly those beyond the requirements found in the Oregon Death with Dignity Act, do not make the law safer. Instead, they create unnecessary barriers, serving as a disincentive for providers to participate in the practice and making it incredibly difficult for terminally ill patients to access the option.

Particularly concerning would be the inclusion of provisions from the California law such as (but not limited to):

Allowing gag orders on information about medical aid in dying as an end-of-life care option and on insurance information

This weakens the integrity of the informed decision process at the end of life. A physician must provide sufficient information to terminally ill patients regarding all available treatment options, the alternatives and the foreseeable risks and benefits of each, so that the individual can make an independent decision regarding their end-of-life healthcare. Failure to inform a terminally ill individual who requests additional information about available end-of-life treatments including medical aid in dying, or failing to refer the individual to another physician who can provide the information, will be considered a failure to obtain informed consent for subsequent medical treatment. Likewise, insurance providers, and possibly even state-funded plans, should be permitted to disclose upon request, whether or not medical aid in dying is a covered service because patients need all relevant information at all stages of decision-making.

Too strictly defining state residency

The California End of Life Option Act limits the way patients can demonstrate their residency to only four ways. This unnecessarily precludes entire populations of otherwise eligible terminally ill individuals.

Imposing limits on the number of requests a terminally ill individual can make for medical aid in dying

This requirement unnecessarily complicates the process by requiring that all requests are made to the same provider. Requiring that the first request be made to the prescribing physician could result in months of delay, particularly in the event the first provider is unwilling to participate. Time is of the essence given the terminally ill individual has a prognosis of death



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within six months.

Requiring a final attestation patient form

This requirement violates a terminally ill person's right to autonomy and choosing the circumstances of their own death. No other end-of-life option requires a patient to do this, and it is completely unenforceable. Such a requirement is unnecessary to protect patients, as those who have obtained medical aid-in-dying medication have already been determined to be free of coercion and capable of making their own medical decisions by two separate physicians, and if necessary a mental health provider.

Failing to protect patient privacy on death certificates

The California law does not require that the patient's death certificate list the underlying terminal condition as the cause of death. That means that the death could be reported as medical aid in dying. This treats patients who make the personal decision to use medical aid in dying differently than patients who choose other means to achieve comfort and symptom relief during the process of death. For example, patients who choose VSED are not required to report that decision, and certainly are not identified in public death records as having chosen this option at the end of their life. The primary purpose of listing the cause of death on a death certificate is to track diseases such as cancer or heart disease to develop public health policy.

As well as the inclusion of additional provisions suggested within the report including:

Requiring the attending physician to attest that patient enrolled in hospice or was informed of other end-of-life services

This is entirely unnecessary to legislate. Providing patients with complete and accurate information about all available options, particularly at the end-of-life is already part of the standard of care. This responsibility should fall to the medical community and not to the legislature.

Requiring the creation and publication of an online guidebook

The clinical guidelines are clearly established in the legislation and grounded in the standard of care. Furthermore, there are multiple resources available for every discipline involved in the practice of medical aid in dying as well as for patients.

Mandating the establishment of training opportunities for the medical community

This too, is unnecessary to legislate and stands to create an unanticipated barrier as we experienced in the District of Columbia. The D.C Death with Dignity Act of 2017 contains this proposed language. Upon implementation, the Department of Health exceeded their authority by mandating any physician willing to practice, any pharmacist willing to dispense and any terminally ill patient seeking medical aid in dying register with the department and complete a



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lengthy training. As a direct result of this burden, not a single patient was able to access this compassionate end-of-life care option in the first year,

While we do recognize the Committee's hesitation to take on medical aid-in-dying legislation as there are other options that may also improve end-of-life care for *all* Virginia residents including clarifying, enhancing and making more accessible POST forms, there are hundreds of terminally ill Virginia residents who want the option of a peaceful death and do not have time to wait. There is nothing to preclude the Committee from making simultaneous recommendations.

We hope that the JCHC will recognize the immense value of expanding choice at the end of life and recommend advancing option 2 to introduce medical aid-in-dying legislation. If you have any questions please do not hesitate to contact me directly via email at [mspencer@compassionandchoices.org](mailto:m Spencer@compassionandchoices.org) or call 571.289.1728.

Respectfully Submitted,
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Regional Campaign & Outreach Manager

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