



Care and Choice at the End of Life

Medical Aid in Dying: Best Practices for Developing Patient-Centered Policies

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Overview

The goal of good end-of-life care is to provide person- and family-centered options that optimize quality of life by anticipating, preventing and treating suffering. Quality care in the final phases of terminal illness addresses physical, intellectual, emotional, social and spiritual needs, and facilitates patient autonomy, access to information and choice in care.

Each person, together with their families and medical team, should be allowed to make the end-of-life care decisions that are personally right for them in the final stages of their terminal illness. Implementing policies that support patient choice, including the option of medical aid in dying, has been shown to improve end-of-life care overall. And for many patients, the mere knowledge that their care team will empower them to make end-of-life care decisions in line with their personal goals and beliefs has a palliative effect and improves quality of life.

This document is intended to provide hospices with best practices and resources for:

- Developing policies and systems supportive of patients who inquire or choose medical aid in dying as part of their palliative care
- Developing policies and systems supportive of staff who choose to provide optimal patient-centered care to patients who inquire about or choose medical aid in dying

The Importance of Adopting Person-Centered and Engaged-Neutrality Policies

The number of jurisdictions that have authorized medical aid in dying is growing. The practice is currently authorized in six states (Oregon, Washington, Montana, Vermont, California and Colorado) as well as the District of Columbia. Approximately 90 percent of people who request aid-in-dying medication as part of their palliative care are enrolled in hospice.



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The hospice team's nonjudgmental care and support of a person's autonomy is critical to the end-of-life experience for that patient and the family. It should never be considered a failure if a patient chooses to obtain or take aid-in-dying medication -- it is only a failure if the person's autonomy is not supported. ~ Ann Jackson, Former CEO of the Oregon Hospice and Palliative Care Association (1988-2008)

It is important for hospices to provide sufficient support and guidance on how to provide the best possible care to patients who choose medical aid in dying as one of their care options. A position of engaged neutrality¹ is one in which medical staff and facilities take no position on medical aid in dying, but affirmatively adopt policies and systems that support both the patients who choose this option and the medical staff who choose to support these patients.

This guidance and support not only affirms patient autonomy, but provides staff with the tools to provide the very best care and avoids placing the entire burden on doctors and staff who may otherwise struggle in isolation to provide care. Engaged neutrality allows for diverse views while acknowledging that engagement is key to responsible patient care. Hospice medical directors and staff should never feel unprepared or isolated when asked by a patient about medical aid in dying. The hospice organization should support them in their choice to support their patients.

"I provided the same compassion, support and care to all my patients. For those patients who chose medical aid in dying, my care was not hastening the time of their death -- the patients were in control the entire time and making their own decisions based on their own values and needs. My care simply demonstrated my respect for their autonomy and decision-making ~Dr. David Grube, Family Physician, End of Life Specialist"

Medical Aid-in-Dying Laws: Eligibility Criteria and Clinical Criteria

Medical aid in dying gives terminally ill people who qualify the option to request, obtain and self-administer medication to die peacefully if their suffering becomes unbearable.

There are four eligibility criteria for medical aid in dying. A person must be:

- an adult
- terminally ill
- given a prognosis of six months or less to live
- mentally capable of making their own healthcare decisions.

Each state's regulatory and procedural requirements differ slightly, but all the laws

¹ A Call for a Patient-Centered Response to Legalize Assisted Dying, John Frye, MA; Stuart J. Youngner, MD, Ann Intern Med.

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include the above eligibility criteria as well as clinical criteria that meet the highest standard of care for the medical practice of aid in dying as described in the Journal of Palliative Medicine.²

These clinical criteria include requirements that the attending physician must inform terminally ill adults requesting medical aid in dying about other end-of-life options including comfort care, hospice care and pain control, and that the terminally ill adult must self-administer the aid-in-dying medication.

Best Practices for Developing a Policy Supportive of Patient Choice

With nearly 20 years of experience providing expert assistance to healthcare communities on the implementation of medical aid-in-dying laws, Compassion & Choices has worked with industry leaders to create a [model policy](#) (See Appendix A) for hospices using an engaged neutrality framework.

Articulating Why Hospices Need a Medical Aid-in-Dying Policy that Supports Engaged Neutrality

- Patients are autonomous and deserve compassionate care, especially at the end of life.
- Staff need to be able to respond to questions about medical aid in dying as well as about their role and responsibilities so they can continue to meet the needs of patients.
- Staff may need organizational guidance and support in order to feel comfortable and safe with their role and responsibilities in the practice of medical aid in dying.
- Patients increasingly choose hospices based upon the level of support a hospice provides to patients considering medical aid in dying. Some doctors and healthcare systems are starting to refer their patients to hospices that have adopted policies that fully support patients who choose medical aid in dying.

What to Consider When Developing a Policy

- Use the attached model policy based upon existing hospice policies in California and Oregon as a starting point.
- Form or ask an existing interdisciplinary committee to draft the policy, and ask for input from staff. Members of the committee might include:
 - An administrator

² Orentlicher, D., Pope, T.M., Rich, B.A. (2015) Clinical Criteria for Physician Aid in Dying. Journal of Palliative Medicine. 18(x): 1-4. Available from: <https://www.compassionandchoices.org/wp-content/uploads/2016/04/Clinical-Criteria-for-Aid-in-Dying.pdf>



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- Clinical staff, including physicians, nurses and licensed clinical social workers
- Spiritual-care staff
- Board representation, if the board is involved in policy development
- Engage in important policy and procedure conversations including:
 - How will the hospice provide support to patients and staff through the process?
 - What type of education will be provided for staff and volunteers?
 - Medical aid-in-dying laws do not mandate participation of any individual including physicians or other healthcare professionals. How will your hospice handle a potential situation where a medical director, staff member or volunteer chooses not to participate or support a patient's pursuit of medical aid in dying? How will your hospice ensure that the person who chooses not to participate feels their choice is understood by peers?

Establishing a Clear Message and Processes in the Policy

While medical aid-in-dying laws outline the specific requirements for a patient to request and obtain an aid-in-dying prescription, hospices will want to provide a clear message of support and compassion to patients and staff (regardless of whether a staff member chooses to participate), and address how requests for medical aid in dying will be received and managed within the hospice care team.

- What is the process when someone inquires about, requests or obtains aid-in-dying medication?
 - How will the hospice provide information and answer questions from the patient and the family regarding the process (request, the medications, self-administration, etc.)? Will a policy statement be placed on the website?
 - Who on staff needs to be informed about a patient inquiry or request?
 - Will the hospice develop a designated work flow and staff person (e.g., social worker) to explore the request for aid-in-dying medication?
 - What are the standards for staff when communicating about and documenting inquiries and requests for aid-in-dying medication?
 - If the hospice physicians are not able or willing to serve as an attending or consulting physician, will the hospice help patients request aid-in-dying medication from their primary doctors?



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- Will the hospice help coordinate with the doctors involved in the request process and with the pharmacy filling the prescription for the aid-in-dying medication?
- What is the process for supporting patients when they take the medication?
 - How does the hospice offer compassionate support to the patient and family if the patient chooses to take the medication? Note: Historically, approximately one-third of patients choose not to take the medication.
- How will staff be supported through the process?
 - What type of education will be provided for staff and volunteers?
 - Note: Under medical aid-in-dying laws, the terminally ill person must self-administer the medication, which means that the person must take the final, voluntary and physical act to ingest the medication. Medical providers and caregivers can be present during the self-administration, and are allowed to prepare medications and hold cups of the medicine or a straw for a patient to drink as long as the patient is the one who always remains in control of whether to ingest the medication.
 - What emotional support resources will be provided for staff and volunteers?
 - Some hospices have annual reviews of medical aid-in-dying cases to evaluate their responses and support of patients who choose this option.

Managing Conscientious Objections

Medical aid-in-dying laws do not mandate participation of any individual including physicians or other healthcare professionals. Anyone may opt out for religious or other reasons. Physicians or other healthcare professionals regularly encounter situations where their values are in conflict with patient values and acting as responsible professionals, make appropriate referrals. The same standard applies in cases of requests for medical aid in dying.

Appendix A - Model Policy

Compassion & Choices has worked with industry leaders to create a [model policy](#) for hospices, which addresses not only establishing an organizational position but processes and protocols.

Appendix B - Tools and Resources

Compassion & Choices is the nation's oldest, largest and most active nonprofit organization committed to improving care and expanding options for the end of life. To



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this end, Compassion & Choices has developed multiple resources available to patients as well as providers.

- A Call for a Patient-Centered Response to Legalize Assisted Dying, John Frye, MA; Stuart J. Youngner, MD, *Ann Intern Med.* 2016;165(10):733-734 DOI: 10.7326/M16-1319 Published at www.annals.org on 27 September 2016, Available from: <https://drive.google.com/file/d/0B3luDjCAxxv7ZnY0TDE1cGd0a0tRSzJmVHhwR2R6V3dEeU5v/view?usp=sharing> - an article about the need for organizations to take a position of engaged neutrality.
- Orentlicher, D., Pope, T.M., Rich, B.A. (2015) Clinical Criteria for Physician Aid in Dying. *Journal of Palliative Medicine.* 18(x): 1-4. Available from: <https://www.compassionandchoices.org/wp-content/uploads/2016/04/Clinical-Criteria-for-Aid-in-Dying.pdf> and supplementary clinical information available from: <https://www.compassionandchoices.org/wp-content/uploads/2016/02/CPG-Supplemental-Data-2015.pdf> - details the current best practices for medical aid in dying.
- The Compassion & Choices Doc2Doc line offers free, confidential telephone consultation with one of our seasoned medical directors, each with years of experience in end-of-life medical care including medical aid in dying. Visit us online at: <https://www.compassionandchoices.org/research/doc2doc-program/> Call 800.247.7421 or email doc2doc@compassionandchoices.org for information.
- The Compassion & Choices Pharmacist2Pharmacist program helps pharmacy professionals provide accurate information and up-to-date care to patients with prescriptions for aid-in-dying medications. It can be difficult to discuss a patient's terminal illness and death — and crucial for pharmacists to knowledgeably consult directly with patients and caregivers about medications intended to bring about a peaceful death. Visit us online at : <https://www.compassionandchoices.org/wp-content/uploads/2016/09/Pharm2Pharm.pdf> or call us anytime at 503.943.6517.
- Multiple Fact Sheets:
 - Medical Aid in Dying Fact Sheet, Available from: <https://drive.google.com/file/d/0B3luDjCAxxv7NkwxMjFRM18zZ1E/view>
 - [Healthcare Professional Organizations that Recognize Medical Aid in Dying](#)
 - Medical Aid in Dying Improves Care at the End of Life Fact Sheet, Available from: <https://drive.google.com/file/d/0B3luDjCAxxv7UTdKemdGbW81Zms/view>



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- Palliative Care and Medical Aid in Dying Fact Sheet, Available from: <https://drive.google.com/file/d/0B3luDjCAxxv7LWdkb29jSXA2UDBqeU56MmkxU3VKN2twNE1j/view>
- Faith-Based Perspectives on Medical Aid in Dying Fact Sheet, Available from: <https://drive.google.com/file/d/0B3luDjCAxxv7ckJ3SGVfdzdCeW8/view>
- Video resources:
 - “Information on Medical Aid in Dying for Terminally Ill People” can be viewed at: https://www.youtube.com/watch?v=juPri_0eN3M&feature=youtu.be
 - “An Introduction to Medical Aid in Dying as Clinical Practice” can be viewed at: <https://www.youtube.com/watch?v=lgO1KuBtBEw&feature=youtu.be>
 - “The Medical Aid in Dying Process and Liability Protections” can be viewed at: <https://www.youtube.com/watch?v=6lC1LeCrplQ&feature=youtu.be>
- Additionally, C&C has local and national teams of doctors, healthcare professionals and volunteers that are trained to provide technical assistance and education on medical aid in dying to hospices in English and Spanish. This includes:
 - A 30- to 60-minute PowerPoint presentation, which includes a 20- to 30-minute review of law-clinical competencies, Oregon experience and time for discussion.
 - Personalized training can also be developed at your request.

To learn more, visit:
www.compassionandchoices.org

For state specific information visit:
<https://www.compassionandchoices.org/Oregon/>
<http://www.endoflifewa.org/>
<https://www.compassionandchoices.org/Vermont/>
<https://www.compassionandchoices.org/montana/>
<https://www.compassionandchoices.org/california/>
<https://www.compassionandchoices.org/colorado/>
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