

End-of-life care and Prop 106

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Compassionate responses to suffering at the end of life

I'm so sick of being sick, can't we just get this over with? If you care for patients with serious or terminal illness, you've likely heard this or statements like it many times. Delivering the bad news of a terminal diagnosis and responding to a patient's suffering in the face of approaching death are never easy.

The Colorado End-of-Life Options Act (CO-EoLOA; see Box 1) changed everything about responding to patients' suffering. The question coming to you might be as oblique as that above or as blunt as: Can you get me that end-of-life prescription? Depending on the position you've taken on medical aid in dying (see Box 2), the answer may now ultimately be "yes."

However, from another perspective, the new law has changed nothing: Any such question requires a compassionate and appropriate response. This article presents insights from the clinical literature and palliative care practice about the desire to hasten death and how to respond to requests for assistance.

There is broad consensus on these points:

- The desire to hasten death is extremely common among people with serious, progressive, chronic or terminal illness. Mostly the desire is fleeting, tending to reassert when symptoms flare, the disease worsens or surrounding circumstances deteriorate.
- In about 10 percent of patients, the desire becomes prominent and persistent; in less than 2 percent, it con-

solidates into suicidal ideation or a determined request for medical assistance in dying.¹

- The etiology of this desire is more often psychosocial-existential-spiritual in nature than physical. Pain and symptoms can worsen such a desire, but it mostly arises from depression, hopelessness, loss of pleasure in life's activities, loss of autonomy and "selfness," or feeling a burden on others.² These causes or symptoms are *identical* in patients who commit suicide and those who seek medical aid in dying or euthanasia. The strongest predictors of the desire to hasten death and suicide attempts are hopelessness, depression, and loss of meaning and purpose.
- Specific interventions to accelerate treatment for depression, strengthen patient autonomy, relieve caregiver burden, enhance dignity, and reframe meaning and hope are available and effective.
- Even explicit requests for help in dying are "paradoxically, requests for help with *living*."³ When such expressions are heard as the proverbial cry for help and efforts are made to alleviate suffering, the desire to die dissipates—even when the efforts are not 100 percent successful. The mere presence of a compassionate listening ear and sincere attempts to address concerns are balm.

It's also common for physicians to be uncomfortable engaging with their patients' expressions of hopelessness, suffering and desire to hasten death. This

Box 1. Colorado End-of-Life Options Act

- Passed by voters as ballot-initiated statute; effective Dec. 16, 2016.
- Allows adult, terminally ill Colorado residents with mental capacity to request and receive a prescription for life-ending medications from their attending physician.
- The attending physician must determine mental capacity, Colorado residency, terminal illness with prognosis of six months or less, and that the patient is making a voluntary, informed decision; counsel the patient on a number of items related to informed decision making; and refer to a consulting physician to confirm terminal diagnosis and prognosis, mental capacity and informed decision making.
- If either physician has concerns about mental capacity to make an informed decision, they must refer the patient to a mental health professional.
- Once the patient is qualified, the attending physician dispenses the lethal medications or transmits a prescription to a pharmacist for pickup by the patient or authorized person.
- The patient may choose to self-administer the drugs, or not. If the drugs are not used, they must be disposed of safely according to specific rules.
- A more complete summary of the Act, and the details of the requirements and process may be downloaded from The Iris Project website: <http://bit.ly/2osx1di> and <http://bit.ly/2pwd8lQ>.

discomfort has several origins:

- Perceived lack of time, clinical skills or knowledge of the related issues.
- Conviction that addressing psychosocial-existential-spiritual issues is beyond the scope of the physician-patient relationship.
- Assumption that depression and hopelessness in the face of inevitable death are not “problems” that are possible to fix.

Such reactions amount to a kind of “therapeutic nihilism”⁴ that leaves patients feeling abandoned in their suffering and only serves to exacerbate a desire to die.

A number of frameworks for appropriate responses are offered for clinicians in different disciplines (noted with an asterisk on extended list of endnotes on www.cms.org). Here is a general outline:

1. **Do some preliminary self-reflection to understand and neutralize your own views about hastened death and medical aid in dying.** Your immediate, nonverbal response will set the tone for the rest of your conversation with patients. If your reaction is dismissive (“You don’t really mean that”), negative (“That’s not something I would ever consider doing”), or judgmental (“It’s not my job to kill patients”), it will not only shut down productive discussion but also could cause real harm. Whatever your views, an open, authentic concern and commitment to addressing your patient’s distress is essential.
2. **Determine the meaning and motivation of the statement from the patient’s perspective.** The first follow-up question can be simply “Tell me more” or “What’s bothering you most right now?” or “What can we do to make your life better today?” Box 3

summarizes some of the likely root concerns of desire-to-die statements.

3. **Explore the patient’s goals of care into the future and out to the end of life.** What is most important to them during this time? What functions are most important to preserve or support? What activities are most pleasurable? What are their biggest fears, worries, concerns? What are their hopes? A productive discussion around goals requires honest descriptions of illness trajectory and options for treatment, including no treatment, and care. Extra support for family and caregivers can be organized through hospice, assisted living or nursing facility placement, home health, caregiver aides, or volunteer networks. Physicians often skirt difficult talks about prognosis or the end of life for fear of extinguishing hope; however, hope can be reframed in realistic possibilities. These possibilities could include: better quality of life, living until a certain milestone, savoring the pleasures of every day, managing pain and symptoms, spending time with family, reflecting on life’s meaning and rewards, or achieving a peaceful death.

4. **Assess for depression and, if indicated, suicidal ideation.** Depression is present to clinically significant degrees in 23 to 44 percent of palliative care patients, about 30 percent of cancer patients and 63 percent of patients who are likely to seek medical aid in dying, but it is notoriously under-recognized and difficult to diagnose in patients with terminal illness. Classic symptoms of depression such as fatigue, changes in appetite, or insomnia can be indistinguishable from symptoms of disease. Intermittent depressed mood can be a normative aspect of the anticipatory grief associated with dying. Thus, depressive disorders in seriously or terminally ill patients are best diagnosed by cognitive symptoms such as anhedonia, loss of self-worth, pervasive and unremitting sadness, hopelessness and despair—all of which are also strong risk factors for suicide in indi-

Box 2. Possible positions with respect to medical aid-in-dying participation

Taking a position on Prop 106 is not just a “Yes, always” or “No, never” choice. Here are some possible positions. These are not prescribed by the law, but reflect the range of stances taken by physicians and agencies in other states where such laws are enacted.

Opt out: “I will not prescribe medical aid-in-dying drugs, nor serve as an attending or consulting physician to qualify patients for medical aid in dying, nor will I assist patients in pursuit of it. However, I will provide appropriate care within my specialty and training, including discussing available choices for treatment and care of the terminal condition and any related distress or concerns.”

Arm’s length: “I respect my patients’ choices, but I will not prescribe medical aid-in-dying drugs, nor serve as attending physician under the Act. I will provide appropriate care for my patient, including discussing available choices for treatment, care of the terminal condition, and any related distress or concerns. If requested, I will refer my patient to external resources for information about medical aid

in dying and to participating physicians. If my patient decides to ingest life-ending drugs, and I am still involved in the patient’s care, I would like to be informed of the planned death.”

Educate and support: “I support my patients’ choices, including a choice for medical aid in dying. I will do my best to identify and address any distress, openly discuss all available options for relief, and provide all needed information. If my patient elects to utilize aid in dying, I will facilitate the process including referring to and coordinating with an attending physician, consulting physician and, if needed, mental health professional. I will not prescribe the medication, but I will remain involved in the patient’s care up to and through death from any cause.”

All in: “I will serve as an attending or consulting physician for patients wishing to utilize medical aid in dying, including supervising the qualification process, keeping and reporting required records, prescribing medical aid-in-dying medications and, if desired, being present with the patient at self-administration of the medications and death.”

Box 3. Possible root concerns of desire-to-die statements and suggested responses

"It's going ok for now, but if I get to the point where I'm wearing diapers, I'm done."

- Fear of future suffering; losses of function, privacy, independence, personal dignity; fear of burdening family members.
- "What concerns you most about the idea of wearing diapers?"
- Probe specifics of expressed concern; clarify trajectory of illness and likely/unlikely scenarios for the end of life; correct misunderstandings or unfounded worry; look for supports or alternatives to minimize distress.

"If all I've got is a few months left, what's the point?"

- Loss of meaning, purpose, self-worth and significance.
- "What would you most like to do with the time you have left?" "What's most important in your life right now?"
- Encourage activities to support finding meaning, for instance writing an "ethical

will," life review, guided reminiscence, dignity therapy, reconciliation, reaching out to family or friends, connecting with faith community or leader.

"I don't want my family waiting on me and wearing themselves out for nothing. Isn't there something you can do?"

- Loss of autonomy; loss of "place" or role in the family; burdening family members, specifically financial concerns, work of caregiving, diverting their time or energy from other activities or family members.
- "How has your illness impacted your family so far?" "What does your family think about taking care of you?"
- Explore practical supports for family caregivers such as hospice, additional paid help, community-based free or low-cost services. Encourage family members to preserve and respect the patient's role and function in family.

"Can't you just give me that knock-out pill I've been hearing about?"

- Seeking reassurance that you would take a request seriously; "testing the waters;" looking for information about how the medical aid-in-dying law might work; may also indicate current suffering; **don't neglect the possibility that the question expresses suicidal intent.**
- "What's bringing this up for you right now?" "Have you had a change in your symptoms or are there other things you're concerned about?" "What can we do for you now to make things better?"
- Explore motivation for question; offer information, if requested, in neutral, factual manner; discuss briefly your position on prescribing lethal medications while still validating patient's concerns and your commitment to providing care; address new or worsening symptoms. If indicated, assess for suicidal ideation.

viduals who are older or ill. Standardized screening for depression can be exhausting for seriously ill patients, and some researchers have found the straightforward question "Are you depressed most of the time?" can be just as accurate as sophisticated assessments. Psychostimulants may offer quicker, more effective relief than antidepressants for patients whose life expectancy is measured in weeks.

5. **Assess for and address new or under-treated physical symptoms and pain and respond to other psychosocial-spiritual issues** to the extent your skills permit. Refer to other professionals as appropriate. Make referrals to community services or other supports for family and caregivers. Consider formally referring your patient for a hospice evaluation or palliative care consult. Palliative-trained professionals have the most robust toolkit for responding to multifactorial suffering.
6. **Reassure your patient that you have heard their concerns and are committed to finding solutions.** Develop

a specific plan of care and schedule follow-up appointments as needed. Coordinate with other professionals, services and supports.

This process is strongly recommended for patients who express any kind of a desire to hasten death. However, it can be employed proactively to more deeply explore and address aspects of suffering before they coalesce into a cry for help. In the very few cases where the desire to hasten death culminates in a determined and explicit request for medical aid in dying, you may proceed according to your personal values or organizational constraints, but always with respect and compassion. ■

Endnotes

1. As an example, a study of patients in Oregon who would have been eligible for physician-assisted death but did not pursue it found that for every 1 person who ingested lethal drugs under the law, 9 made a serious first request to their physicians, and 200 considered it (Tolle, Tilden, et al., 2004).
2. Financial worries are almost never cited by patients as a motivating concern;

however, they may play a role in the perception of being a burden on family.

3. Monforte-Royo, Villavicencio-Chávez, Tomás-Sábado, & Balaguer, 2001, p. 799.
4. Chochinov, 2001.

See the extended list of endnotes at www.cms.org/articles/prop-106-may-june.

Jennifer Moore Ballentine, MA, is president of The Iris Project (www.irisproject.net), an independent health care consulting company based in California but serving clients nationwide. With deep roots in Colorado, Ballentine held several leadership positions in hospice and palliative care education in the state, notably as executive director of Life Quality Institute. Immersed for several years in the research, policy and clinical implications of medical aid in dying, she has been closely involved with provider education on the California End-of-Life Option Act and observing close-up the operational and ethical challenges medical aid in dying presents. Since mid-January, she has offered 11 all-day programs on the Colorado End-of-Life Options Act in nine locations around Colorado.