

Res. A-09-19

Title: Clear Communication and Upholding the Social Contract When Responding to Patients with Terminal Illness and/or Existential Distress

Introduced by: Clarissa Kripke, MD, FAAFP

WHEREAS, California is a majority-minority state with high rates of racial, ethnic, cultural, linguistic, educational and religious diversity, and

WHEREAS, misunderstanding of prescriptions and other information and instructions given by physicians is extremely common, and

WHEREAS, there is evidence that explicit information leads to better comprehension, and,

WHEREAS, using a euphemism such as “medical-aid-in-dying” is subject to misinterpretation, and

WHEREAS, California Academy of Family Physicians (CAFP) members treat many people for whom English is a second language or who require translators, and

WHEREAS, California’s End of Life Option Act (EOLOA) requires medical translators to assess a patient’s understanding, a requirement which is outside their scope of practice and which violates their ethical commitments, and

WHEREAS, CAFP members treat many people from cultures which de-emphasize individual self-determination in medical decision-making and who are deferential to the opinions and needs of authority figures, physicians, or family members, and

WHEREAS, regardless of prognosis, prescribing drugs with the intention of hastening a patient’s death violates long-standing, medical ethical principles and is illegal in most states, and

WHEREAS, the recent change in California’s law authorizing physicians to prescribe lethal drugs to terminally ill patients does not represent a change in best practice or ethics, and

WHEREAS, the prohibition against harming or intentionally hastening the death of a patient is a key boundary which supports the trust required for an effective doctor-patient relationship, and

WHEREAS, a patient doesn’t have to request or receive a lethal prescription to have their care negatively affected by physicians or physician organizations exposing the belief that some people are better off dead, and

WHEREAS, prescribing lethal drugs is neither best practice nor consistent with long standing medical ethics as a response to patients who express existential distress, now, therefore be it

RESOLVED: that CAFP rescind policy A-07-17, and be it further

RESOLVED: that CAFP reaffirm and recommit to implement CAFP’s existing policy on End-of-Life Care which describes appropriate responses to patients who express existential distress, and be it further

RESOLVED: that CAFP include representatives of vulnerable populations when developing and delivering CME on End-of-Life Care.

Speaker’s Notes: Pursuant to CAFP bylaws, resolution A-07-17 was submitted to the Board for review in July 2017. The resolution called for the American Academy of Family Physicians (AAFP) to reject the term “assisted suicide” to describe the process whereby terminally ill patients of sound mind ask for and receive prescription medication they may self-administer to hasten death should their suffering become unbearable. It acknowledged that use of medical aid in dying is an ethical, personal end-of-life decision that should be made in the context of the doctor patient relationship, and asked AAFP to submit a resolution to the House of Delegates of the American Medical Association that calls on that organization to: 1) reject use of the term “assisted suicide” when referring to the practice of medical aid-in-dying; and 2) modify its current policy with language that recognizes medical aid-in-dying as an ethical end-of-life option when practiced where authorized and according to prescribed law.

The CAFP Board considered and passed the resolution at the July 2017 Board meeting and reported on the resolution at the CAFP All Member Advocacy Meeting in March 2018.

The CAFP AAFP delegation took action on the policy as called for in the resolution by submitting to the AAFP: Resolutions 403: Medical Aid in Dying Is an Ethical End of Life Option and 405: Reject “Assisted Suicide” Terminology in Aid in Dying to the 2018 Congress of Delegates. Both resolutions were adopted with substitute language. AAFP’s new policies are:

That the American Academy of Family Physicians acknowledge that use of medical aid-in-dying is an ethical, personal end-of-life decision that should be made in the context of the doctor-patient relationship.

That the American Academy of Family Physicians seek to modify the current American Medical Association (AMA) policy on end-of-life care with language that recognizes medical aid-in-dying as an ethical end-of-life option when practiced where authorized and according to prescribed law.

That the American Academy of Family Physicians reject the term “assisted suicide” to describe the process whereby terminally ill patients of sound mind ask for and receive prescription medication they may self-administer to hasten death should their suffering become unbearable.

That the American Academy of Family Physicians urge the American Medical Association (AMA) and its CEJA to reject use of the term “assisted suicide” when referring to the practice of medical aid-in-dying.

In response to submission of a subsequent resolution to the CAFP Board on communicating Board actions to the membership, the Board reviewed the process by which A-07-17 was reviewed and passed, and concluded it had acted in accordance with CAFP Bylaws.

Also of note, CAFP's Committee on Continuing Professional Development (CCPD) has been actively engaged in the development and implementation of EOL educational activities, including, but not limited to, the EOLOA, palliative care for primary care and documenting advanced directives and advance care planning. The CCPD would welcome engagement from representatives of vulnerable populations for review of current resources and development of new ones.

Fiscal Note:

The resource implications of rescinding policy, reaffirming existing policy and seeking input from representatives of vulnerable populations are likely to be minimal. If the CAFP Board determines that passage of this resolution also requires advocating against previously passed policy at AAFP, more significant staff costs may be incurred.

SUBMITTED BY THE AUTHOR

- 1. PROBLEM STATEMENT: What specific practice problem does this resolution seek to solve, or, if this resolution pertains to a proposed new CAFP policy or change of policy, what issue does it seek to address?**

A therapeutic doctor-patient relationship requires trust and clear communication. Trust requires boundaries. Physicians are human and subject to unconscious biases, just like everybody else. Our personal beliefs and experiences impact the care we provide. They inform the words and frameworks we use to counsel patients. Patients also internalize negative messages from family and friends, media, and trusted authority figures. When people make life and death decisions about their health care, they are influenced by the opinions of their doctors and the policies of professional organizations. There is an inherent power differential in the doctor-patient relationship. Managing that power differential requires extraordinary care. The most important boundaries are to do no harm, seek informed consent, and avoid intentionally hastening a person's death. CAFP policy A-07-17 commits CAFP to change these core ethical principles, and to obscure that fact by using misleading language to talk about it.

Timeline and context:

In March of 2015 Resolution A-07-15, "Death with Dignity and End of Life Options for People with Terminal Illnesses" was submitted. The authors of the California End of Life Option Act legislation were invited to present at the All Member Advocacy meeting to seek CAFP's support for the legislation. Significant concerns about the resolution were raised. No members, aside from the authors of the resolution, testified in favor. The CAFP board declined to adopt it, and instead adopted a new policy on end-of-life care.

In June 2016, the End of Life Option Act was passed in California in a special session on health care funding. It was passed without full debate. It's legal status has been challenged both on the basis of the process by which it was passed, and the substance of the law. It is making its way slowly through the courts and its future is uncertain.

In 2017, the same author who submitted A-07-15, submitted a new resolution, entitled, “Medical Aid-in-Dying Is not ‘Assisted Suicide’”. The resolution was received by the board after the 2017 All Member Advocacy Meeting. Without notification or input from the membership, the CAFP board adopted it as Resolution A-07-17. The policy:

1. requires CAFP to use a confusing and misleading euphemism when discussing prescriptions of lethal drugs to terminally ill patients
2. directs the Academy to declare physician assisted suicide, “ethical”
3. requires CAFP to represent physician assisted suicide as a personal, private matter, instead of a societal issue which impacts social policy and vulnerable populations
4. changes the social contract between CAFP physicians and the public
3. directs CAFP to disseminate these ideas and values to the national AAFP organization

The risks of this policy change, especially for vulnerable populations, deserves to be discussed by the full membership, in an open forum. Because CAFP members represent a privileged group who may not be fully aware of the concerns and experiences of less privileged populations, before considering such an important policy change, members must have the opportunity to educate themselves about the ethical and practical concerns that impact the people they serve.

2. PROBLEM UNIVERSE: Approximately how many CAFP members or members’ patients are affected by this problem or proposed policy?

All CAFP members treat diverse populations including vulnerable populations. Proponents of physician-assisted suicide emphasize that the numbers of people who request lethal prescriptions are small, and few requests come from members of vulnerable populations. It is true that the potential *benefit* of CAFP’s current policy is limited to a small number of relatively, educated, privileged people. However, the potential *harm* is much broader. Once physicians and the public accepts the premise that some people’s lives are so burdensome, tragic, full of suffering, meaningless, hopeless, and undignified that they would be better off dead, the logical corollary is that ending their lives can be considered an act of mercy. This opens the door to a variety of abuses:

- proposing suicide as a solution to people who are experiencing existential distress or who are in untenable social or economic situations
- secondary gain
- premature withdrawal of life saving care for people with disabilities based on false assumptions about quality of life
- explicit or implicit messages that people have a responsibility to die to relieve family, insurance providers, health care providers, or taxpayers
- expansion to people who have existential distress but no terminal illness
- expansion to active euthanasia of adults and children with and without consent

3. WHAT SPECIFIC SOLUTIONS ARE YOU PROPOSING TO RESOLVE THE PROBLEM OR POLICY:

Prior to adopting A-07-17, CAFP's board implemented sound policy on end-of-life consistent with medical ethics and values. I propose that the board could simply rescind A-07-17 and reaffirm its commitment to that policy. (The text of the relevant CAFP policies are listed at the end of the resolution.)

4. WHAT EVIDENCE EXISTS TO 1) INDICATE THAT A PROBLEM EXISTS; OR 2) THAT THERE IS NEED FOR A NEW OR REVISED POLICY?

Efforts to normalize assisted suicide and the ethical justifications are of particular concern to the disability community. Proponents of the practice frequently cite fear of being disabled as the primary reason that they feel that life is not valuable. This is obviously a threat to people with disabilities who value their own lives and whose opportunities and access to care is limited by false assumptions about their quality of life. Belief that living with disability means poor quality of life, easily becomes a self-fulfilling prophesy. For example, one early adopter of the end of life option act reported that he prescribed a patient a lethal prescription because she was despondent due to being "bed bound." A more appropriate response would have been to provide her a Hoyer lift, wheelchair, aide and transportation.

Instead of lethal prescriptions, people with loss of function due to chronic disease and terminal illness need:

- services and supports
- home modifications
- transportation
- personal assistance
- person-centered planning
- support for decision-making that allows them to continue to direct their lives to the extent possible
- help maintaining their circle of support
- friends
- inclusion
- support to participate in family and community

What they are typically offered is primarily medical treatments to cure disease or manage symptoms. This is important, but not sufficient. There is consensus that people shouldn't be coerced into ending their lives because of lack of access to the support and care they need. We are a long way from providing it, even to people with significant social capital and financial resources.

More information about the concerns of the disability community can be found at:

- Disability Rights and Education Fund: Assisted Suicide Laws: <https://dredf.org/public-policy/assisted-suicide/>
- Euthanasia Blues: <https://www.youtube.com/watch?v=8Mwj8TUrbWg>
- Facts about disability and quality of Life: <https://www.independentliving.org/docs3/gil199.html>

- Not Dead Yet: <https://notdeadyet.org/not-dead-yets-articles>
- Panel on Societal Issues and the End of Life Option Act
https://www.youtube.com/watch?v=FHIdQLo_8QA&list=PLPdSQGGMt89eDiKtQtbZmgGmWA8aWMU4Z&index=5&t=0s

5. PLEASE PROVIDE CITATIONS:

Carr, L. Legalising assisted dying is dangerous for disabled people. Not compassionate. Sept. 9, 2016. The Guardian. <https://www.theguardian.com/commentisfree/2016/sep/09/legalising-assisted-dying-dangerous-for-disabled-not-compassionate>

Crane, S. Aid in Living, not dying. Feb. 24, 2016. The Baltimore Sun. <https://www.baltimoresun.com/news/opinion/oped/bs-ed-hb404-con-20160224-story.html>

Davis, T. C., Federman, A. D., Bass, P. F., 3rd, Jackson, R. H., Middlebrooks, M., Parker, R. M., & Wolf, M. S. (2009). Improving patient understanding of prescription drug label instructions. *J Gen Intern Med*, 24(1), 57-62. doi:10.1007/s11606-008-0833-4

Kheriaty, A. The dangerously contagious effect of assisted-suicide laws. Washington Post. Nov 20 2015. https://www.washingtonpost.com/opinions/the-dangerously-contagious-effect-of-assisted-suicide-laws/2015/11/20/6e53b7c0-83fb-11e5-a7ca-6ab6ec20f839_story.html?noredirect=on&utm_term=.8b0d94026b4f

Kripke, C. Patients with Disabilities. Avoiding Unconscious bias when discussing Goals of Care. 2017. American Family Physician. <https://www.aafp.org/afp/2017/0801/p192.pdf>

Mattlin, B. 'Me Before You' perpetuates the idea that the disabled should consider suicide. May 31, 2016. Chicago Tribune. <https://www.chicagotribune.com/news/opinion/commentary/ct-suicide-disability-me-before-you-perspec-0601-md-20160531-story.html>

Tolle, S., Tilden, V.P., Drach, L.L. Characteristic and Proportion of Dying Oregonians who Personally Consider Physician-Assisted Suicide. *J of Clin. Ethics*. 2004.15(2): 111-2.

US Census Quick Facts, California: <https://www.census.gov/quickfacts/fact/table/ca/PST045217>

Res. A-07-17 – Medical Aid-in-Dying Is Not “Assisted Suicide”

RESOLVED, That the American Academy of Family Physicians reject the term “assisted suicide” to describe the process whereby terminally ill patients of sound mind ask for and receive prescription medication they may self-administer to hasten death should their suffering become unbearable, and be it further

RESOLVED, That the American Academy of Family Physicians acknowledge that use of medical aid in dying is an ethical, personal end-of-life decision that should be made in the context of the doctor patient relationship, and be it further

RESOLVED, that the American Academy of Family Physicians submit a resolution to the House of Delegates of the American Medical Association that calls on that organization to: 1) reject use of the term “assisted suicide” when referring to the practice of medical aid-in-dying; and 2) modify its current policy with language that recognizes medical aid-in-dying as an ethical end-of-life option when practiced where authorized and according to prescribed law. *BOD 11.4.17*

End-of-Life Care EXT

CAFP recognizes the need for appropriate end-of-life care, which may include: Appropriate treatment of physical pain, recognizing that in some cases such treatment may hasten the end of life; Compassionate care which is interpersonal, existential or spiritual, and may include working together with social workers, hospice, clergy, family and friends; and Eliciting and addressing a patient's reasons for considering physician aid-in-dying. Only through dialogue can family physicians, their patients and society as a whole continue to explore what is reasonable and morally appropriate. The highest-quality health care is an outgrowth of a partnership between the patient, the family and the health professional or professional team.

Within the context of this continuing relationship, family physicians must seek the underlying causes of suffering at the end of life, and then aggressively implement measures to correct them. Appropriate education in palliative care and medical management, advanced communication skills to discover the patient’s wishes and value choices, and appropriate sharing of decision-making with the patient and the patient’s family can go a long way toward alleviating suffering and improving care at the end of life. Family physicians should continue to provide assistance in dealing with dying patients’ symptoms, needs and fears.

NOTE: This policy was adopted by the CAFP Board of Directors 4.24.15 as part of the Legislative Affairs Committee Report and replaces policies under the topic of TERMINAL ILLNESS including Compassionate Care RC-1-00, 2/00 CoD, Physician-Assisted Suicide RC-1-00, 2/00 CoD, Statement on Terminal Illness Care 5/93 BoD and Terminal Illness and Physician-Assisted Death A-10-96 CoD. CAFP took a neutral position on pending legislation to enact the End of Life Options Act in 2015.

B-13-18 Open, Member-Driven Process for Policy Development for CAFP

RESOLVED: That a process for obtaining member comments and input on resolutions received between meetings of the All Member Advocacy Meeting be developed; and be it further

RESOLVED: That CAFP members have an opportunity to comment on and provide input into the proposed new process for soliciting member input on resolutions received between meetings of the All Member Advocacy Meeting for consideration by the Board of Directors before such a policy is adopted;