

RECOMMENDATIONS

FOR PATIENT PROTECTION

>For Medical Professionals Implementing the California EOL Option Act<

HIGHLY RECOMMENDED READING

Physician-Assisted Suicide in Oregon: A Medical Perspective, Drs. Herbert Hendin & Kathleen Foley, Michigan Law Review, June 2008.

<http://dredf.org/wp-content/uploads/2012/08/Hendin-Foley-Michigan-Law-Review.pdf>, or go to <http://dredf.org/public-policy/assisted-suicide/> and scroll down to C.1.

The California End of Life Option Act legalizes a new medical treatment. Like any medical treatment, it needs indications, guidelines, protocols, and outcomes.

Goals should include:

- A. To protect vulnerable persons in times of weakness. This means protecting poor, elderly, and disabled people, and those in other vulnerable groups, from indifference, prejudice, abuse, exploitation, devaluation, and psychological and financial pressure to end their lives.
- B. To protect the medical profession's integrity and ethics, and maintain physicians' role as their patients' healers and advocates; and
- C. To avoid a gradual shift toward enlarging the criteria for eligibility, and tolerance for violations of the stated eligibility criteria.

All medical professionals should establish more thorough protocols and require additional data collection than the minimal standards in the law. Hospitals and health care organizations should reach for the highest standards and best practices.

None of the inquiries described below need to be burdensome on patients or their families. Medical records, which already have extensive confidentiality protections under prior law, may be reviewed by all treating professionals and subpoenaed in case of legal question.

Guidelines should be developed by ethics committees in collaboration with psychiatry and palliative care services. The development of these guidelines should be open to discussion and debate. There should be checklists for periodic review.

PROTOCOLS SHOULD INCLUDE

1. Patients requesting assisted suicide should present their major reasons for wanting it. They should fill out a questionnaire on why they want assisted suicide, and present their own reasons rather than checking off a pre-prepared checklist of reasons.
2. Provide the requesting patient with frequently asked questions that patients can ask their doctors.
3. Inform patients of treatments for cure or to extend life. Involve family members in the discussion. When telling patients all their options, doctors should also find ways to assist patients to obtain needed or desired options, rather than merely telling patients about the options.
4. Every requesting patient should be evaluated by a second physician who is independent of the first, from a master list of physicians who are willing to serve in this role.
5. Every requesting patient should receive a detailed assessment by a psychiatrist or member of the ethics committee.
6. Every requesting patient should receive a psychiatric evaluation. Require a mental health evaluation by practitioners who have access to information about palliative care.
7. Every requesting patient should receive a competency evaluation. Psychiatric evaluation should be based on a revised competency standard that reflects suicidal risk rather than merely a "decision making" standard.
8. If pain is a key issue, the patient should have a pain consultation with an expert in pain management. Require pain specialist assessment and treatment.
9. If the patient is terminally ill or dying, they must have a palliative care consultation by a certified palliative care doctor.
10. The patient should be offered a spiritual counselor.
11. Any request for euthanasia or assisted suicide should trigger appropriate suicide prevention measures.
12. There should be an economic assessment of the patient via a short interview. This need not be burdensome. The patient should be asked if there are economic factors in their request for death, and whether there are financial and/or family pressures present. If there is any indication of economic pressure, a series of questions should be asked, including: "Do you owe the hospital money?" and "Are you on MediCal?"

If the patient acknowledges wanting to save their family money, they should be allowed to speak with a financial advisor at the hospital. The financial advisor should determine how real the patient's belief is about the financial difficulties. For example, some patients believe they can't pay for their medicines. Yet doctors can sometimes write the pharmaceutical company to determine if the company will provide the medication. Hospitals have other financial services that should be considered in evaluating whether the patient's financial concerns are real. The

patient should be helped to understand that a social worker can assist them to obtain resources.

Based on all available information, the ethics committee should evaluate whether there is undue economic pressure.

>NOTE ON THE ABOVE ASSESSMENTS<

These assessments provide a significant advantage in clarifying how contextualized and how well-informed a patient's decisions are. Many patients are afraid of their doctors, afraid to talk about dying, and experience extreme power issues in relationship to medical personnel. This is exacerbated by the fact that some doctors spend little or no time assisting patients to sort out these factors. Good psychiatric and palliative care evaluations can shed light on what is really happening with these patients.

13. All doctors and health care professionals who are interfacing with the patient on this issue must have expertise in communication about delivering bad news, talking about choices at the end of life, and discussing options for care. This is a skill set that research shows many physicians do not have. Such personnel should have taken the appropriate course(s) and be certified in palliative care.
14. An independent, neutral witness should be present when a patient takes lethal drugs, to provide transparency. Consider requiring a physician to be at the bedside.
15. Given the nature of California as a highly multicultural state, all of the above recommendations need translators, staff with cultural competence, and written material in languages and formats that all patients can use.
16. The death certificate should say that the patient participated in the California End of Life Option Act.

DEVELOP PROTOCOLS FOR VARYING OUTCOMES

17. Protocols should be developed for a variety of possible situations. For example, if the patient has major depression or questionable competency, how will the hospital or medical system address it? E.g., a review by the ethics committee or an ethics consultation.
18. What should be done if the patient's prognosis is five years?
19. How is a patient to be cared for after requesting lethal drugs if the person is deemed ineligible? Some care should be provided that aids the patient and discourages the possibility that they will act inappropriately on suicidal wishes.

TRAINING

20. There should be additional training for healthcare providers, as palliative care is not adequately included in training curricula for healthcare workers; clinical exposure is limited or absent during rotations and specialization courses; palliative care specialization courses are not sufficiently available; and/or continuing education in palliative care is absent or inadequate.¹

21. Develop and implement training modules for medical and mental health professionals in the social model of disability and the effects of discrimination on the physical and mental health of people with disabilities.

DATA-GATHERING, EVALUATION, AND QUALITY IMPROVEMENT

22. Each health care system should have an independent committee that reviews all cases of use of the California End of Life Option Act, for the purpose of discovering any questions or difficulties, in order to develop recommendations for improving the system. A quality improvement program is necessary, along with thorough documentation of the process. Patient confidentiality can be assured, as names need not be used. Establish a hospital, institution, or health care plan oversight body to track and analyze:
 - A. Requests for lethal drugs, what doctors said “no” and why, etc.
 - B. Medical conditions, socio-economic circumstances, location and demographic factors of persons making the requests, as well as professionals making recommendations on eligibility.
 - C. Availability and efficacy of alternative interventions including access to medical treatment, disability related supports, mental health supports, and palliative care.
 - D. Outcomes of requests authorized and denied.
 - E. Trends in the above factors.
23. Establish a hospital, institution, or health care plan mechanism to investigate anomalies in case records, and work with local law enforcement to follow up on problems.
24. Create a hospital, institution, or health care plan mechanism for families and other interested parties to trigger an investigation when a person has died due to what may be an untracked case of assisted suicide or purported assisted suicide, or an incident of abuse, coercion, or other irregularity.
25. Ensure that sanctions reflect a commitment to punishing crimes against people with disabilities and those who are ill, equally to crimes against non-disabled and well persons.
26. Assisted suicide should be subjected to the same standards as are used for other medical procedures. There should be transparency in full peer review.

OUTPATIENT SITUATIONS

27. Procedures in outpatient clinics and for patients at home should have similar protections to those described above, to the greatest extent practicable. Health care providers and insurers should consider what checklists should be used for patients in their homes. Every doctor in California who participates in this treatment should document extensively in notes and fill out a questionnaire in real time (not six months later). Every patient should be evaluated by a

second physician who is independent of the first, from a master list of physicians who are willing to serve in this role. All this information should be reported to the state.

28. The family or caretakers of any patient who does not use the lethal prescription should bring that prescription back to the pharmacy. It should be returned in order to be destroyed.
29. Home-based consumer-directed personal assistance services (also known as attendant services) are less expensive than institutional care and provide better outcomes for users, including an increased sense of control, dignity, and life satisfaction.

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¹ Human Rights Watch, October 2015, Submission to External Panel on Options for a Legislative Response to Carter v. Canada.