

State of California—Health and Human Services Agency California Department of Public Health



June 9, 2016 16-07

TO: LOCAL REGISTRARS OF BIRTHS AND DEATHS

CHIEF DEPUTY REGISTRARS OF BIRTHS AND DEATHS

COUNTY CORONERS AND MEDICAL EXAMINERS

FUNERAL DIRECTORS COUNTY RECORDERS

SUBJECT: REPORTING CAUSES OF DEATH FOR END OF LIFE OPTION ACT

This All County Letter provides information regarding accurate reporting on the cause of death on the California Certificate of Death when a person uses an aid-in-dying drug to end his or her life as authorized by the End of Life Option Act (the "Act").

Certifiers (physicians, coroners, and medical examiners) should not report the cause of death as "pursuant to End of Life Option Act," or use similar phrases. Instead, the California Department of Public Health (CDPH) recommends that they report the underlying terminal disease as the cause of death. This approach complies with applicable law; will best ensure the reliability and usefulness of data collected from the death certificate for state, national, and international surveillance purposes; and will effectuate the California Legislature's intent regarding the confidentiality of patients' participation in the Act.

The Act does not itself provide guidance regarding reporting of the cause of death on the California Certificate of Death when an individual exercises rights under the Act, other than to provide that such a death, occurring pursuant to the Act, is not suicide. Therefore, certifiers should not report suicide as a cause or related condition to cause of death when an individual properly exercises his or her rights under the Act.

However, reporting "pursuant to End of Life Option Act," or using similar phrases, as a cause of death would not be consistent with applicable law. Specifically, Health and Safety Code Sections 102825 and 102860 require certifiers to identify on the certificate of death the "disease or condition directly leading to death, antecedent causes, other significant conditions contributing to death." Because the "End of Life Act" is not a "disease," "condition," or "antecedent cause" of death, it should not be listed on the death certificate.



Instead, CDPH recommends that certifiers report the underlying terminal disease. Such reporting advances the data collection and analysis purposes for which death certificates are used. From a public health perspective, in terms of collecting vital statistics data that informs policy decision-making by the State, reporting the underlying condition(s) that began the chain of events resulting in an individual's death is of paramount usefulness.

Further, such reporting is consistent with national and international practices on data gathering regarding mortalities. The State Registrars in all of the States report cause of death data drawn from death certificates to the National Center for Health Statistics (NCHS), where the cause of death is coded according to the International Classification of Diseases, Rev 10 (ICD-10). CDPH fulfills this reporting obligation using data from California Certificates of Death. These coding rules are standardized, not only nationally but internationally, so that causes of death can be compared and understood in a standard fashion.

CDPH has been advised by NCHS that the term "pursuant to the End of Life Option Act" (or similar terminology) would be coded as R99 (unknown cause of death) relative to Section 107 of the California Certificate of Death and would therefore negate the accuracy and value of the data in terms of analyzing national and international public health trends. Therefore, to maintain a uniform observance and maintenance of a satisfactory system of registration, the State Registrar advises that language such as "pursuant to the End of Life Option Act" (or similar terminology) not be recorded in Section 107 or Section 112 of the California Certificate of Death, and instead report the underlying terminal disease.

Such reporting also appears to best advance the Legislature's intentions when enacting the Act, and particularly that participation in the Act be confidential. The Act contains language designed to protect the confidentiality of participation. Stats. 2015, 2nd Ex. Sess. 2015, ch. 1, § 2. ("The interests in protecting the privacy rights of the patient and his or her family in this situation strongly outweigh the public interest in having access to personally identifiable data relating to services.") Because California is an "open records" state, meaning that the public can access information on an individual's death certificate, notations on the death certificate regarding participation in the Act (e.g., "pursuant to End of Life Option Act") would become a matter of public record. Accordingly, CDPH recommends that such terms not be recorded in Section 107 or Section 112 of the California Certificate of Death, and that the underlying terminal disease be reported instead.

CAUSES OF DEATH FOR END OF LIFE OPTION ACT Page 3

If you have questions regarding this matter, please contact Ms. Laurie Taylor at (916) 650-6872.

Sincerely,

Original signed by:

Tony Agurto, MPA Deputy State Registrar Assistant Deputy Director Center for Health Statistics and Informatics