

**REPORT TO THE THIRTIETH LEGISLATURE
STATE OF HAWAII
2020**

**PURSUANT TO ACT 2 SESSION LAWS OF HAWAII 2019
(HB2739 H.D. 1)**

Prepared by the Department of Health Office
of Planning, Policy, and Program Development
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Executive Summary

The information compiled in this report is an analysis of the implementation of the Our Care, Our Choice Act including any implementation problems and any proposed legislation. It covers activities from the establishment of the OCOCA board on July 31, 2018 through December 26, 2019.

To date, there were a total of twenty-seven (27) qualified patients who received aid-in-dying prescriptions. Of those twenty-seven, nineteen (19) patients expired. Of those patients who expired, fifteen (15) patients died due to some form of cancer, fourteen (14) ingested aid in dying medications, and five (5) did not ingest the aid-in-dying medication. Eighteen (18) patients who expired had private insurance and/or Medicare and one (1) indicated United Health Care as the insurer. DDMP2 was the primary aid in dying medication prescribed with DDMA being least prescribed at six (6) times. Twelve (12) attending physicians wrote prescriptions during this reporting period. Only one attending physician was located on the neighboring islands on Hawaii island. **There were no reported complications due to ingesting the medications.**

The eligibility process from the first oral request to the date of receipt of the written prescription was an average of 34 days. The average waiting period was 27 days with the shortest waiting period being 20 days.

The major findings since implementing the OCOCA are 1) lengthy waiting periods (i.e. 20 days is too long); 2) patient and provider difficulty navigating the process amongst non-integrated, private practicing health care providers as opposed to integrated health care systems such as Kaiser Permanente, and 3) access to available and practicing health care providers especially mental health care providers. These findings were collected from a health care provider summit on October 21, 2019.

Introduction

Act 2, Session Laws of Hawaii (SLH) 2018, authorized Hawai'i residents with a terminal illness and six (6) months or less to live may request medical-aid-in-dying prescriptions under the OCOCA. To help patients and providers understand the process required by law, the DOH launched a new page on its website where all required forms, instructions, and frequently asked questions can be accessed.

The law establishes eligibility criteria and safeguards to ensure a secure, compassionate, and patient-centered end-of-life process. There are also additional regulatory requirements to address concerns about misuse. Patients interested in seeking a prescription are encouraged to enroll in hospice.

To meet eligibility criteria patients must be:

1. Age 18 or older and a Hawai'i resident;
2. Able to take the prescribed medication themselves;
3. Able to make two oral requests not less than 20 days apart to their attending physician;
4. Able to provide one written request after meeting eligibility criteria from all three (3)

- health care providers; and
- 5. Mentally capable to make an informed decision.

Details of the eligibility process may be accessed on the DOH’s website here:
<http://health.hawaii.gov/opppd/ococ/>

Implementation Review and Analysis

OCOCA Advisory Board

The DOH implemented Act 2 by establishing a five-member OCOCA Advisory Board that held its first meeting on July 31, 2018 followed by consecutive meetings on August 31, 2018, November 29, 2018, and December 7, 2018.

The OCOCA Board Members are listed in the table below:

Member Role	Board Member
Chair – Director of Health	Bruce S. Anderson, Ph.D.
Medical Educator	Lee Buenconsejo-Lum, M.D.
Palliative Care Specialist	Rae Seitz, M.D.
Non-Medical Community Member	Malachy Grange
Hospice Care Specialist	Brenda Ho

OCOCA Advisory Board Staff: There were two DOH employees who served as staff to the OCOCA Advisory Board. Staff members located in the Office of Planning, Policy, and Program Development are Lorrin J. Kim, Chief Policy Officer, and Laura K.M. Arcibal, State Telehealth and Health Care Access Coordinator.

Permitted Interaction Groups:

Two permitted interaction groups were established following board approval. One permitted interaction group was formed to review and comment on the development of the website and forms. The second permitted interaction group was formed to address community resources. Under the review, guidance, and final approval of the OCOCA Advisory Board, the website and its forms were finalized and made accessible online before the law went into effect on January 1, 2019.

Board Meeting Minutes:

Board meeting minutes may be accessed here: <https://health.hawaii.gov/opppd/meetings-reports/>

OCOCA Advisory Board discussions resulted in the development of a website to 1) inform both patients and their families, and health care providers of the law and its process; and 2) provide forms for both providers and patients implement the process, document eligibility, and report information required under Act 2. To start the eligibility process, patients and providers must access the website and download its forms here:
<https://health.hawaii.gov/opppd/ococ/>

On the website, patients are informed to start early and talk with their attending physician. Patients are strongly encouraged to enroll in hospice to ensure all end of life care options are available to them and to become familiar with eligibility requirements as he or she works closely with their attending physician and his or her health care team. Health care providers are also informed on the website about the law, the eligibility timeline and criteria, and the OCOCA required forms reportable to the DOH.

Following execution of the website and its forms, the DOH received its first completed forms in March 2019. On the first report, it took 48 days between the first oral request to the date of the patient's written prescription. The waiting period between the first oral request and second oral request was 24 days. To date, the average is 34 days between the first oral request to the date of written prescription compared to 48 days. And the current average waiting period is 27 days. The longest waiting period of one patient was 100 days between the first and second oral request compared the minimum requirement of 20 days.

Community inquiries to the DOH are minimal via email or phone call and are responded to promptly. Information requested is generally on the gathering of information about the OCOCA for which the response is either to direct the individual to the website or answered directly.

Community Education Events

To further inform patients and health care providers, continuing medical education events were held on February 1 and 2, 2019 at the Queen's Conference Center Auditorium and University of Hawaii, John A. Burns School of Medicine, respectively. Other learning opportunities were provided in the private sector, for example at the annual meeting of the Hawaii Pharmacists Association and the annual meeting of the Health Information Management Association of Hawaii.

On October 21, 2019, a health care provider summit was held to capture feedback from participating health care providers, care navigators and support staff. Notes collected from the facilitated meeting captured the group's feedback that is summarized in the bulleted items below.

- Recognized the need for patient continuity and navigation such as the use of care navigators to assist patients through the process in identifying and accessing participating providers in the community;
- Recognized the need for continuity and navigation of the process amongst providers in the community versus within large integrated systems such as Kaiser Permanente;
- Recognized the importance of developing relationships amongst community providers in the palliative care, hospice care, and health care provider communities especially in private practice versus large integrated systems such as Kaiser Permanente;
- Recognized the challenges in accessing available and participating health care providers and especially mental health care providers;
- Recognized process recommendations whereas the waiting period is too long (i.e. patient illness progresses whereby he or she is unable to swallow the medications or limited access to attending physicians who then take leave); and

- Recognized concerns about medication disposal and need for information about its process.

Legislative Recommendations

In closing, the DOH recommends the following changes to the OCOCA.

1. Waiver of waiting periods if the attending provider and consulting provider agree that patient death is likely prior to the end of the waiting periods; and
2. Authorizing advance practice registered nurses to serve as attending providers for patients seeking medical aid in dying.

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A BILL FOR AN ACT

RELATING TO CHAPTER 327L.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1 SECTION 1. Section 327L-1, Hawaii Revised Statutes, is
2 amended by amending the definition of "attending provider" to
3 read as follows:

4 ""Attending provider" means a physician licensed pursuant
5 to chapter 453 or an advanced practice registered nurse licensed
6 pursuant to chapter 457 who has responsibility for the care of
7 the patient and treatment of the patient's terminal disease."

8 SECTION 2. Section 327L-11, Hawaii Revised Statutes, is
9 amended to read as follows:

10 "~~§~~**§327L-11**~~§~~ **Waiting periods.** (a) Not less than
11 twenty days shall elapse between the qualified patient's initial
12 oral request and the taking of steps to make available a
13 prescription pursuant to section 327L-4(a)(12). Not less than
14 forty-eight hours shall elapse between the qualified patient's
15 written request and the taking of steps to make available a
16 prescription pursuant to section 327L-4(a)(12).

17 (b) If the attending provider and consulting provider
18 agree that the patient is likely die prior to the end of the

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1 waiting periods, the attending provider may waive any of the
2 waiting periods."

3 SECTION 3. Section 327L-12, Hawaii Revised Statutes, is
4 amended to read as follows:

5 "~~§~~327L-12~~§~~ **Medical record; documentation**

6 **requirements.** The following shall be documented or filed in a
7 qualified patient's medical record:

8 (1) All oral requests by the qualified patient for a
9 prescription to end the qualified patient's life pursuant to
10 this chapter;

11 (2) All written requests by the qualified patient for a
12 prescription to end the qualified patient's life pursuant to
13 this chapter;

14 (3) The attending provider's diagnosis and prognosis and
15 determination that the qualified patient is capable, acting
16 voluntarily, and has made an informed decision;

17 (4) The consulting provider's diagnosis and prognosis and
18 verification that the qualified patient is capable, acting
19 voluntarily, and has made an informed decision;

20 (5) The counselor's statement of determination that the
21 patient is capable, and does not appear to be suffering from
22 undertreatment or nontreatment of depression or other conditions

_____.B. NO._____

Report Title:

Our Care, Our Choice Act

Description:

Amends chapter 327L to authorize advance practice registered nurses to serve as attending providers for patients seeking medical aid in dying, and authorizes attending providers to waive waiting periods for patients likely to die prior to the end of waiting periods.

The summary description of legislation appearing on this page is for informational purposes only and is not legislation or evidence of legislative intent.