Kōkua Mau's Let's Talk Story Program

Hope Young
Advance Care Planning Coordinator

Navigating Serious Illness and End-of-Life Options
Behavioral ECHO

Who is *Kokua Mau*?

- 501(c)3, community benefit org., statewide (not a state agency)
- Membership – hospices, health plans, hospitals, long term care, spiritual care, EOA, Maui County Office on Aging
- Passionate volunteers across the state

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Three areas of activity

1. Work with people who may be facing serious illness & their loved ones to understand the decisions they may need to make – as early as possible!
2. Provide professional networking & training
3. Change the System - Policy & Legislation

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“…modern medicine has yet to make even one person immortal. Therefore, at some point, more treatment does not equal better care.”

--Dr. Ira Byock

A Movement for Change

Kokua Mau is leading a *movement* that aims to make advance care planning and open communication about care and support for those with serious illness and their loved ones, including end-of-life care *the cultural norm*

the conversation project

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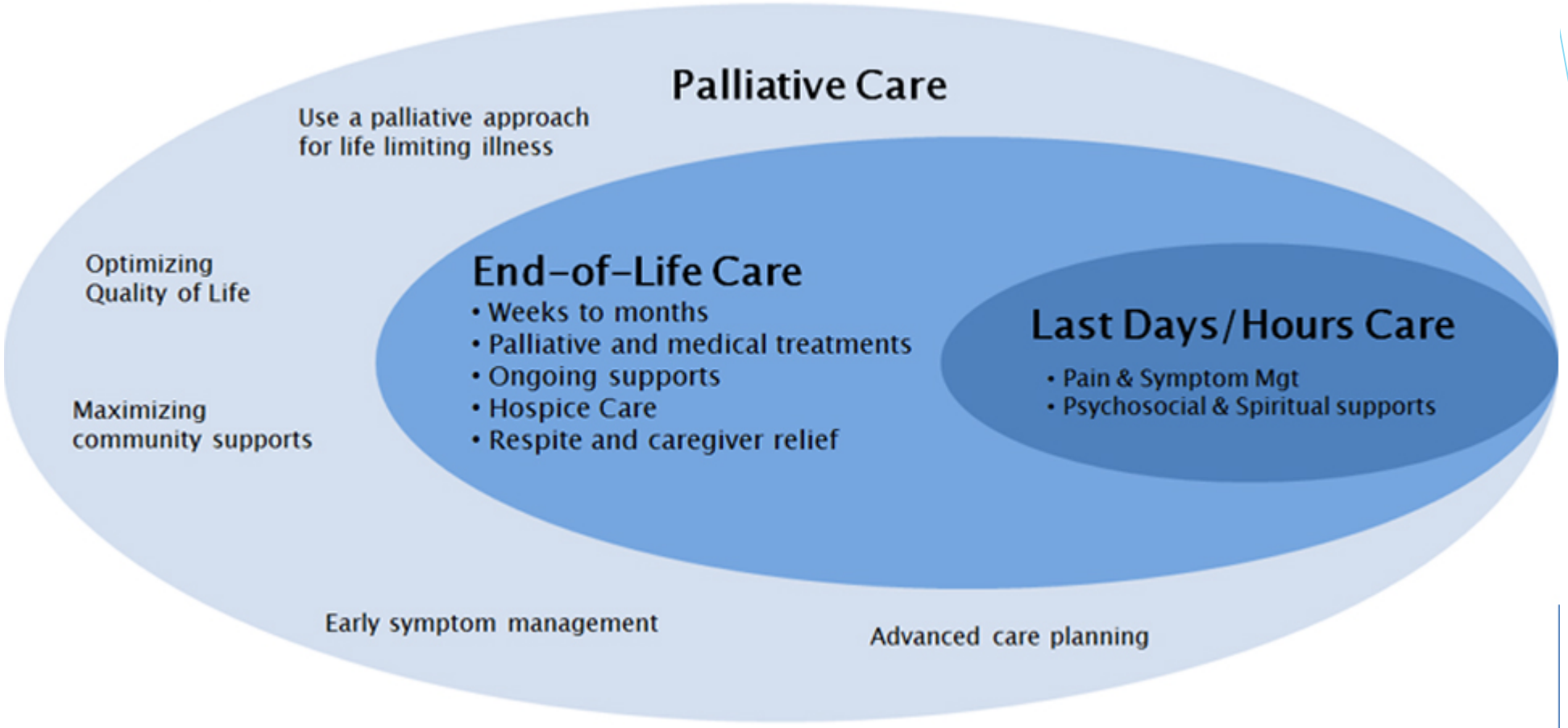

End-of-life care is hospice care

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Palliative Care

- “Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

- Palliative care is provided by a specially trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. This care is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.”

Defined by the Center to Advance Palliative Care (CAPC)

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Palliative Care

- To palliate is to “ease the symptoms without curing the underlying condition” Merriam-Webster
- Often is confused with hospice
- Hospice care is a type of Palliative care, but Palliative care is not a type of hospice.

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Signs that Palliative Care is needed

- Frequent ER visits or calls to the doctor
- Difficulty managing medications
- Diminished activities of daily living i.e. managing finances, driving, grocery shopping, preparing meals, light housekeeping
- Pain, fatigue, swelling in feet & legs, nausea

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When should Palliative Care begin?

- At the time of diagnosis
- Throughout the course of the illness
- Those with medical issues could live longer, and have a better quality of life by accessing palliative care early

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Why Palliative Care?

- Early, upstream interventions to live well with your illness
- Focuses on providing relief from the symptoms and stress of a serious illness
- The goal is to improve quality of life for both the patient and the family
- Provides an extra layer of support

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Why Palliative Care -con't

- Provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other providers
- It is appropriate at any age and at any stage in a serious illness
- Can be provided along with curative treatment

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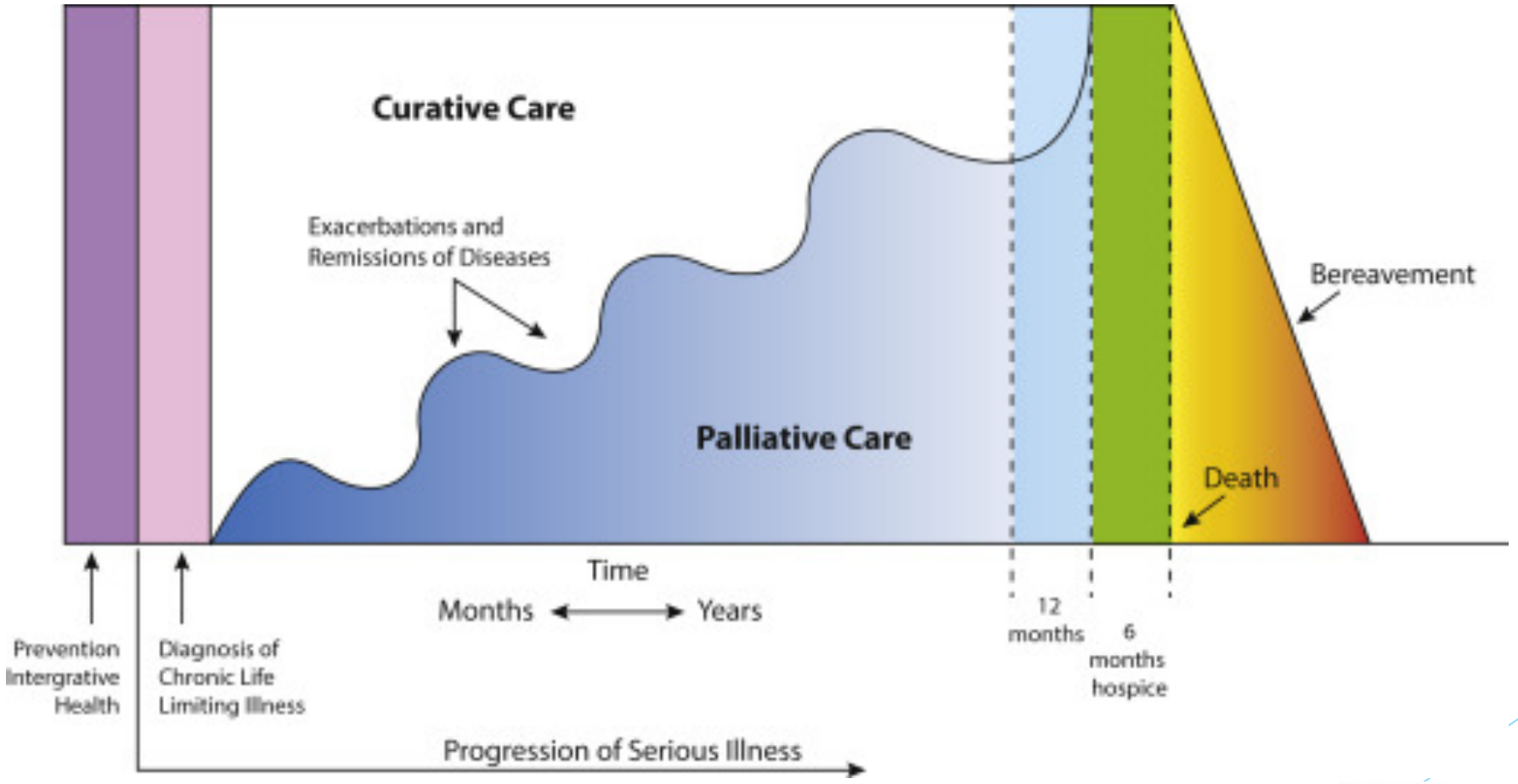
Use of palliative care throughout serious illness and frail health



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Where can you find Palliative Care?

1. In-patient
2. Out-patient - QMC Supportive Oncology Clinic
3. In-home
   - HMSA: Supportive Care
   - UHA: Concurrent Care
   - VA: Supportive Care Benefit (only available in Hawaii)
   - Hawaii Care Choices (Hilo): Kupu Care
   - Kauai Hospice
   - Bristol Hospice on Oahu (new program)
   - Attention Plus Home Health
   - Navian Hawaii
   - Islands Supportive Services

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Myths and Facts about Palliative Care

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Myth:

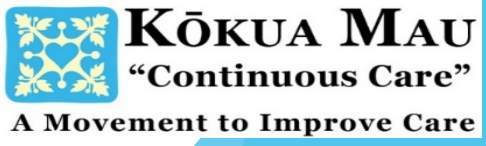
- Palliative care is only for pain management
- Palliative care is the same as hospice
- Palliative care is only for cancer patients
- Palliative care means stopping all treatments

Fact:

- Pain management is part of palliative care, which is a philosophy of care with an interdisciplinary approach during a serious illness
- In palliative care, individuals can continue with **curative** treatment, and is not necessarily end-of-life care
- Palliative care is for anyone facing a serious illness and is not based on diagnosis or prognosis
- Palliative care is an additional layer of support while receiving curative treatments

Poll and check in

- Before this session:
- True or False
- Any questions about Palliative Care?



End-of-life options: Hospice

"The way we die lives on in the memory of those who survive"

--Dame Cicely Saunders,

founder of the modern hospice movement

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Preliminary poll on Hospice

- When do we call hospice?
- Where do you get hospice?

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Hospice Care

- Specialized type of care for those facing a life-limiting illness, their families and their caregivers. Individuals with a diagnosis of 6 months or less to live.
- Addresses the patient's physical, emotional, social and spiritual needs.
- Helps the patient's family, loved ones and caregivers
- Takes place in the patient's home or in a home-like setting.

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Hospice Care – con't

- Concentrates on managing a patient's pain and other symptoms so that the patient may live as comfortable as possible and make the most of the time that remains.
- Believes the quality of life to be as important as length of life
- Available on all islands
- Hospice care allows a natural death without unwanted interventions while providing support to the individual and loved ones at the end-of-life

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Why Hospice?

- Hospice offers patient-centered care in a team approach; Physician, Nurse, Social Worker, Aide, Spiritual Advisor for each hospice patient including bereavement support for loved ones

- Hospice allows individuals to avoid unwanted ER visits and hospital stays

- Hospice supports loved ones after death

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The Cool Kids Club

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When is it time for Hospice Care?

- Multiple visits to the ER or the Doctor
- Weight loss, increase in falls
- Difficulty getting out of bed or a chair
- Sleeps most of the time, unable to stay awake
- Recurrent infections and skin breakdowns
- Decision to stop any curative treatments

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Change the focus:

"What's the matter with me?"

TO:

"What matters to me…"

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Thoughtful reflection:

- If faced with a terminal and life-limiting illness, how would I want to spend the rest of my time? Where would I want to be?

- Hospice will focus on quality of life, rather than quantity of life. What does quality look like for you?

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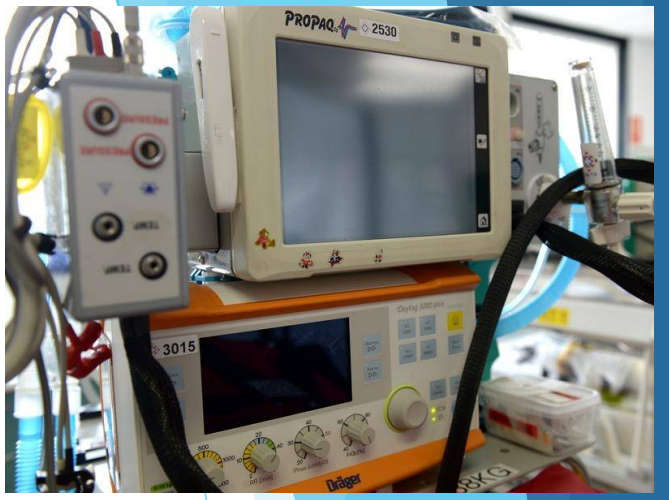
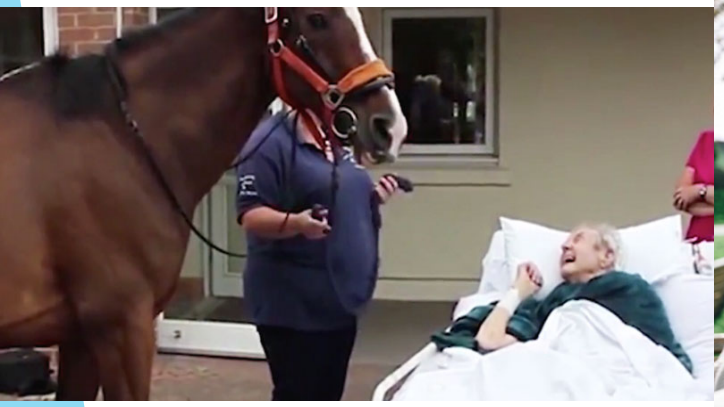


When curative treatments aren't effective and precious time could be doing and/or being with someone else, what would you choose?

Hospice will focus on quality rather than quantity. What does quality look like for you?



13 Facts (not Myths) about Hospice

1. **Hospice is not a place -** people receive services where they live.
2. **Loved ones and relatives are part of the team caring for the hospice patient.** They are supported by the hospice team.
3. **Hospice is not a last resort.** When cure is no longer possible, hospice can do many things to control pain, reduce anxiety, offer spiritual and emotional support, and improve quality of life for terminally ill people and their families.

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Facts about Hospice (con't)

4. **Hospice has no religious affiliation.**

- Chaplains and other spiritual counselors come from all faiths and no faith.

- Respect all cultures and points of view.

- Lend support and discuss the patient's and the family's feelings.

5. **Hospice is not just for cancer patients but for anyone with a terminal illness.**

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Facts about Hospice (con't)

6. **Hospice care is not expensive.**

7. **Hospice does not forego medications or treatments** but uses state-of-the-art medications & palliative treatments to relieve pain and symptoms to keep patients comfortable.

8. **Hospice does not mean anyone has failed the patient.**

9. **Hospice is not about giving up;** it's about living in comfort and dignity for the time one has left.

10. **Hospice is about living well up until the time of death**

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Facts about Hospice (con't)

11. **Hospice does not make death come sooner,** it can actually make people live longer!

12. **Morphine prescribed to a hospice patient does not cause premature death** but helps maintain Quality of life until the end of life

13. **Hospice is NOT euthanasia or physician assisted suicide –** the dying process is not speeded up.

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It is possible to live well, even in the face of serious illness

Remember there are many ways to help:

- Comfort – physically and mentally
- Connection – spiritually, family, friends, socially
- Preparation – personally and medically
- Guidance through a rite of passage

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Be proactive with learning treatment options

- Receiving a diagnosis is difficult. Explore your treatment options and discuss with your provider what matters most to you.

- If you are asked to complete a POLST (Providers Orders for Life Sustaining Treatment) due to a serious illness, ask for a palliative consult.

- Have thoughtful and meaningful conversations about your wishes for care with loved ones and complete an Advance Health Care Directive. Share it with your provider and your loved ones.

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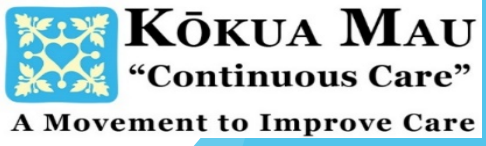
Poll and check in

- When should we call hospice?
- Where can we get hospice?

Questions about hospice?



Our Care, Our Choice Act (OCOCA)

- Many terms for Medical Aid in Dying
  - “Physician Assisted Suicide”
  - “Medically assisted death”
  - “Euthanasia”, “suicide”
  - “Medically hastened death”

Language is important to mindful of.

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Legal Requirements

- Took effect January 1, 2019
- Adult resident of Hawaii with a prognosis of less than six months
- Mentally capable of making decisions
- Acting voluntarily
- Capable of self administering medication

Recommended enrollment in a hospice program

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Patient Requests

- Two oral request separated by no more than 20 days (current legislation could change this)
- One written request witnessed by two people, at least two days before prescription is written
- A mental health evaluation
- One signed final attestation

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Provider Roles

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- **Attending physician** is a licensed physician defined as having "responsibility for the care of the patient and treatment of the patient's terminal illness.“
- **Consulting provider** is a licensed physician "who is qualified by specialty or experience to make a professional diagnosis and prognosis regarding the patient's disease.“

Mental Health Counseling

- Mental health counseling must be provided.
- Can be Psychiatrist, Psychologist or Licensed Clinical Social Worker.
- Must confirm person is “capable”
- Must confirm patient is not suffering from under-treatment or non-treatment of depression or conditions which may interfere with ability to make an informed decision.
- May be a tele health encounter.

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Other provisions

- Death certificate shall list the terminal disease as the immediate cause of death
- Unused medication shall be delivered for disposal to the nearest qualified facility
- No Effect on Life Insurance or Annuity
- Act does not authorize euthanasia
- Organizations, facilities, and providers may participate or refuse to participate

Special Consideration

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- Federal prohibition against use of federal monies for any activities associated with “assisted suicide”
- Still trying to understand this limitation
- Medicare beneficiaries/federally insured may have to pay out of pocket
- This should not prevent you from discussing MAID and all options for end of life care
  - Office visit is covered if linked to chronic condition

Key Points to Remember

- Attending physician responsible for ensuring all requirements are met
- Providers who are allowed to complete steps in the process are clearly defined
  - Not everyone can complete process
- Participation in the process is completely voluntary
- Some populations will probably have more difficulty accessing this choice
- It is an out-of-pocket expense

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Key things to remember

- Individuals who request to use OCOCA, should be enrolled in hospice during the waiting period
- If OCOCA is being considered, it is recommended to start the process early
- There are limited providers who are participating
- Providers and health systems are not required to participate

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Current legislation could change rules

- Potentially changing the timeline to reduce the waiting period
- Potentially changing the requirements to include Nurse Practitioners to be prescribers
- Potentially changing rules to make exceptions for people very close to death

Reasons for Requesting MAID

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Patient Concern	Oregon	Washington
Loss of Autonomy	91.6%	86%
Less able to engage in enjoyable activities	89.7%	86%
Loss of Dignity	78.7%	69%
Losing control of bodily functions	48.2%	49%
Burden on family/friends/caregivers	41.1%	52%
Inadequate pain control or fear of it	25.2%	35%
Financial implications of treatment	3.1%	13%

For More Information & Forms

State of Hawaii Department of Health

- health.hawaii.gov/opppd/ococ/

Kōkua Mau

- kokuamau.org

California Coalition for Compassionate Care

- https://coalitionccc.org/

Join Us at Kokua Mau!!

Resources and other activities

- Join Kokua Mau Mailing List
- Download materials from the Kokua Website – look for the Tool Kit
- Use the new translations
- Request a speaker from Kokua Mau's **Let's Talk Story** Program – We are ready to talk with your church or other group!

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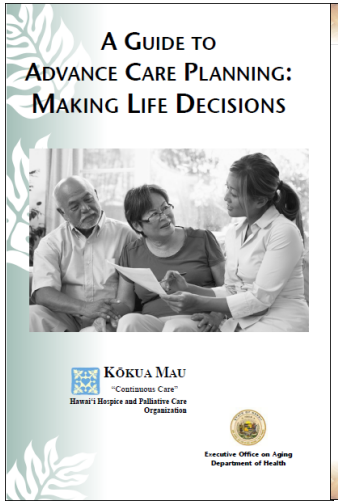
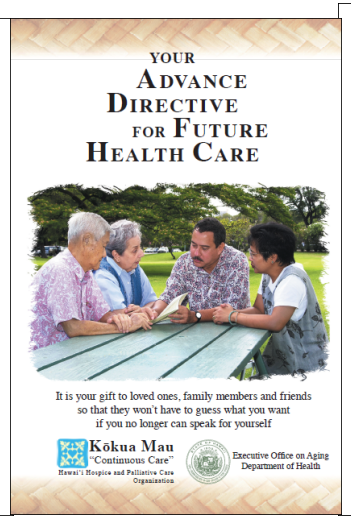
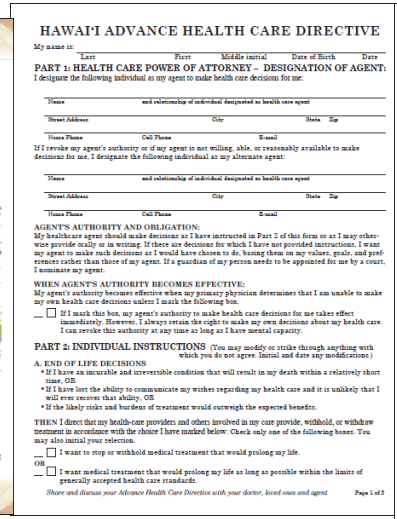
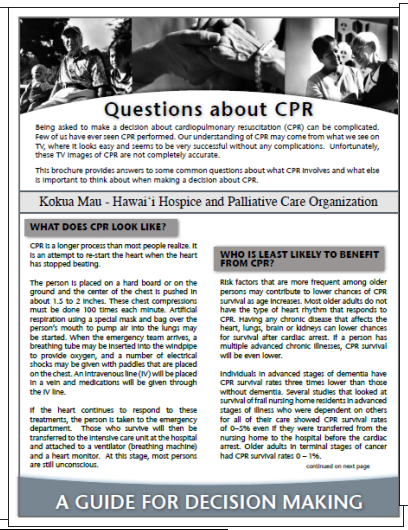
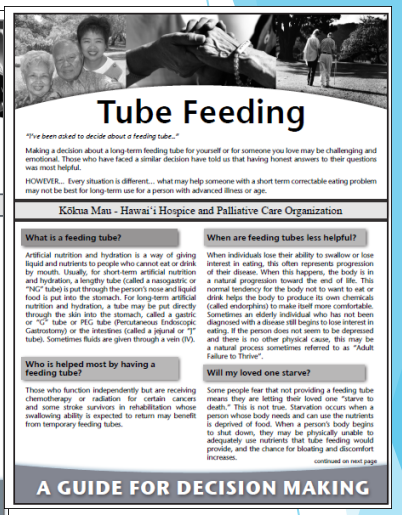
Kokua Mau Resources

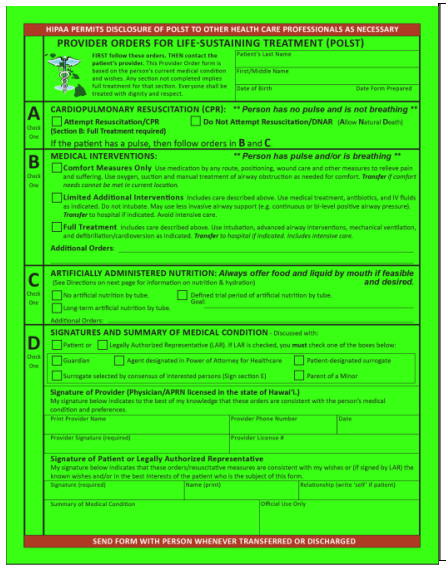


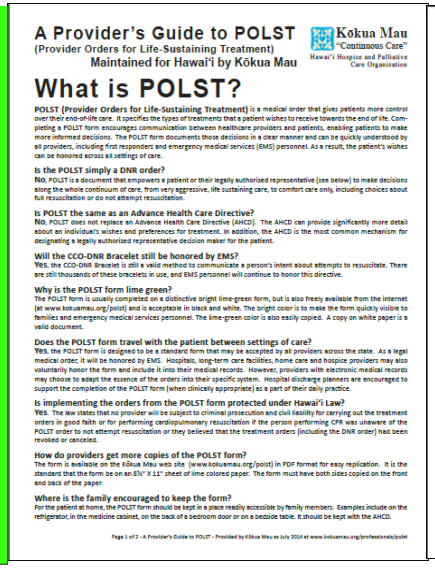


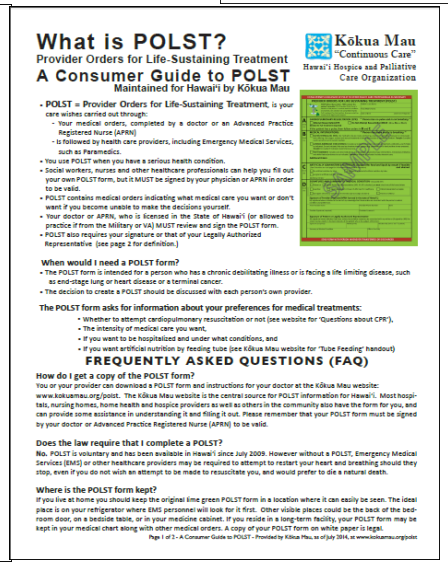












Chinese simplified Hawaii **Advance** Health Care **Directive**
Chinese traditional Hawaii **Advance** Health Care **Directive**
Ilocano Hawaii **Advance** Health Care **Directive**
Japanese Hawaii Advance Health Care Directive
Korean Hawaii **Advance** Health Care **Directive**
Marshallese Hawaii Advance Health Care Directive
Spanish Hawaii **Advance** Health Care **Directive**
Tagalog Hawaii **Advance** Health Care **Directive**
Tongan Hawaii Advance Health Care Directive
Vietnamese Hawaii **Advance** Health Care **Directive**

Since June 2016 the ***Hawaii POLST Form*** is available in 10 languages.

- Chinese simplifiedPOLST Form for Hawai'i
- Chinese traditional POLST Form for Hawai'i
- Ilocano POLST Form for Hawai'i
- Japanese POLST Form for Hawaii
- Korean POLST Form for Hawaii
- Marshallese POLST Form for Hawaii
- Spanish POLST Form for Hawai'i
- Tagalog POLST Form for Hawai'i
- Tongan POLST Form for Hawaii
- Vietnamese POLST Form for Hawai'i

http://www.kokuamau.org/

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