### Kōkua Mau's Let's Talk Story Program

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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



#### 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



"...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* 







#### **Palliative Care**

Use a palliative approach for life limiting illness

Optimizing Quality of Life

Maximizing community supports

End-of-Life Care

- · Weeks to months
- · Palliative and medical treatments
- Ongoing supports
- Hospice Care
- · Respite and caregiver relief

Last Days/Hours Care

- · Pain & Symptom Mgt
- Psychosocial & Spiritual supports

Early symptom management

Advanced care planning

End-of-life care is hospice care



#### **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)



#### **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.



### 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



#### 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



#### 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



### Why Palliative Care -con't

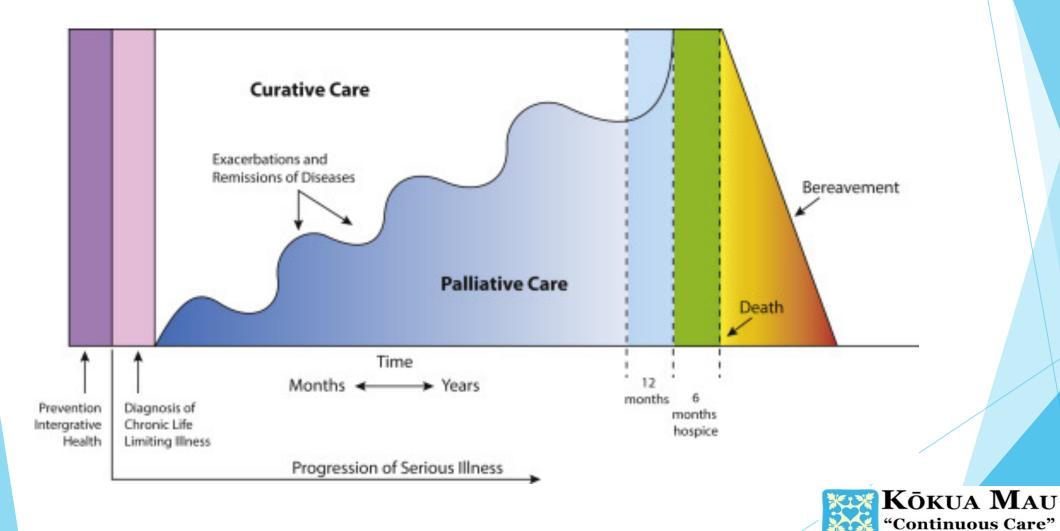
Provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other providers

It is appropriate at any age and at any stage in a serious illness

Can be provided along with curative treatment



# Use of palliative care throughout serious illness and frail health



A Movement to Improve Care

#### 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



# Myths and Facts about Palliative Care

# 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,

KŌKUA MAU
"Continuous Care"

A Movement to Improve Care

founder of the modern hospice movement

### Preliminary poll on Hospice

▶ When do we call hospice?

Where do you get hospice?



#### **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.



#### 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 endof-life



#### 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



#### The Cool Kids Club





### 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



#### Change the focus:

"What's the matter with me?"

TO:

"What matters to me..."



#### 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?











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.



### 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.



# 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



# 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.



# 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



#### 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.



#### 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.



### 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



# **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



## **Provider Roles**



- 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 undertreatment or non-treatment of depression or conditions which may interfere with ability to make an informed decision.
- May be a tele health encounter.



# 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**



- 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

# 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

# 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



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/

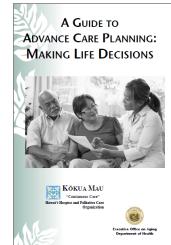
## Join Us at Kokua Mau!!

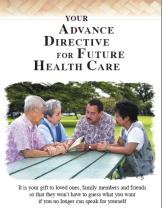
## Resources and other activities

- ▶ 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!



## Kokua Mau Resources





"Continuous Care"

Paral' Hospice and Palliative Care

Department of Health

™Kōkua Mau

## HAWAI'I ADVANCE HEALTH CARE DIRECTIVE

First Middle initial Date of Birth Date DART 1. HEALTH CARE DOWER OF ATTORNEY - DESIGNATION OF AGENT-

If I revoke my agent's authority or if my agent is not willing, able, or reasonably available to make decisions for me, I designate the following individual as my alternate agent:

and relationship of individual designated as health care agent

WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE. agent's authority becomes effective when my primary physician determines that I am unable to make own health care decisions unless I mark the following box.

If I mark this box, my agent's authority to make health care decisions for me takes effect immediately. However, I always retain the right to make my own decisions about my health care I can revoke this authority at any time as long as I have mental capacity.

PART 2: INDIVIDUAL INSTRUCTIONS (You may modify or strike through anything with which you do not serve. Initial and date any modifications.)

\* If I have lost the ability to communicate my wishes regarding my health care and it is unlikely that I will ever recover that ability, OR

• If the likely risks and burdens of treatment would outweigh the expected benefits.

THEN I direct that my health-care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below: Check only one of the following boxes. You may also initial your selection.

I want to stop or withhold medical treatment that would prolong my life.

I want medical treatment that would prolong my life as long as possible within the limits of generally accepted health care standards.



Kokua Mau - Hawai'i Hospice and Palliative Care Organization

If the heart continues to respond to these treatments, the person is taken to the emergency department. Those who survive will then be transferred to the intensive care unit at the hospital and attached to a ventilator (breathing machine) and a heart monitor. At this stage, most persons are still unconscious.

🖥 Kōkua Mau

Hawai'i Hospice and Palliative

The person is placed on a hard board or on the ground and the center of the chest is pushed in about 1.5 to 2 inches. These chest compressions must be done 100 times each minute. Artificial Risk factors that are more frequent among older persons may contribute to lower chances of CP survival as age increases. Most older adults do not have the type of heart rhythm that responds to

Individuals in advanced stages of dementia have CPR survival rates three times lower than those without demential several student in tolled at stages of lines who were dependent on others to all of their case showed CPR survival rates of 0-0% even if they were transferred from the untimp home to the hospital before the cardiac arrest. Other adults in terminal stages of cancer had CPR survival rates 0 - 1%.

# **Tube Feeding**

Making a decision about a long-term feeding tube for yourself or for someone you love may be challenging and emotional. Those who have faced a similar decision have told us that having honest answers to their question

Kōkua Mau - Hawai'i Hospice and Palliative Care Organization

Artificial nutrition and hydration is a way of giving liquid and nutrients to people who cannot eat or drink by mouth. Usually, for short-term artificial nutrition and hydration, a lengthy tube (called a nasogastric or a natural progression toward the end of Ille. This

Those who function independently but are receiving chemotherapy or radiation for certain cancers and some stroke survivors in rehabilitation whose swallowing ability is expected to return may benefit and successful to the control of the control o

A GUIDE FOR DECISION MAKING

## A GUIDE FOR DECISION MAKING



A Provider's Guide to POLST Kokua Mau (Provider Orders for Life-Sustaining Treatment) Maintained for Hawai'i by Kōkua Mau

## What is POLST?

POLST (Provider Orders for Life-Sustaining Treatment) is a medical order that gives patients more control over their end-of-life care. It specifies the types of treatments that a patient withes to receive towards the end of life. Completing a POLST form encourages communication between healthcare providers and patients, enabling patients to make more informed decisions. The POLST form documents those decisions in a clear manner and can be quickly understood by all providers, including first responders and emergency medical services (EMS) personnel. As a result, the patient's wishe can be honored across all settings of care.

Is the POLST simply a DNR order?

NO, POLST is a document that empowers a patient or their legally authorized representative (see below) to make decisions along the whole continuum of care, from very aggressive, life sustaining care, to comfort care only, including choices about full resouchables or do not attempt resuscitation.

No, POLT does not replace an Advance Health Care Directive?

No, POLT does not replace an Advance Health Care Directive (AHCD). The AHCD can provide significantly more detail about an individuosit whites and preference for treatment in addition, the AHCD is the most common mechanism for designating a legally authorized representative decision maker for the patient. Is POLST the same as an Advance Health Care Directive

Why is the POLST form lime green?

The POLST form is usually completed on a distinctive bright ime-green form, but is also freely available from the internet
(in www.satuamu.org/post) and is exceptable in back and white. The bright color is to make the form quickly visible to
families and emergency medical services personnel. The time-green color is also easily copied. A copy on white paper is a

Is implementing the orders from the POLST form protected under Hawai'i Law?

How do providers get more copies of the POLST form?

The form is available on the Kölus Mau web site (www.kolusmasu.org/polst) in PDF format for easy replication. It is the standard that the form be on an 8%" X 11" sheet of time colored paper. The form must have both sides copied on the front

Where is the family encouraged to keep the form?

For the patient at home, the POLST form should be kept in a place readily accessible by family members. Examples include on the refrigerator, in the medicine cabinet, on the back of a bedroom door or on a bedside table. It should be kept with the AHCD.

## What is POLST? Provider Orders for Life-Sustaining Treatment

A Consumer Guide to POLST POLST = Provider Orders for Life-Sustaining Treatment, is your

care wishes carried out through:
- Your medical orders, completed by a doctor or an Advanced Practice

want if you become unable to make the decisions yourself.
Your doctor or APRN, who is licensed in the State of Hawaii (or allowed to POLST also requires your signature or that of your Legally Authorized

## When would I need a POLST form?

The POLST form is intended for a person who has a chronic debilitating illness or is facing a life limiting disease, such as end-stage lung or heart disease or a terminal cancer. The decision to create a POLST should be discussed with each person's own provide

The POLST form asks for information about your preferences for medical treatmen

If you want to be hospitalized and under what conditions, and

## FREQUENTLY ASKED QUESTIONS (FAQ)

How do I get a copy of the POLST form?

How do I get a copy of the POLST form?

The state of the POLST form of the POLST

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 simplified POLST 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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