

Kōkua Mau's Let's Talk Story Program

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What is Palliative Care?
Navigating Serious Illness



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Today's Agenda

- Learn more about Palliative Care: What is it and who could benefit from it
- Benefits of Palliative Care: how can it support individuals and loved ones facing serious illness
- Community Resources: where can individuals get Palliative Care
- Family Testimonial

Who is *Kōkua Mau*?



- 501(c)3, community benefit org., statewide (not a state agency) which began in 1999
- Membership - health plans, hospitals, hospices, long term care, spiritual care, home health, Aging Network
- Passionate volunteers across the state
- Concentrate on the continuum of care: ACP, including POLST, palliative care, hospice care and bereavement

Three areas of activity



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Work with people who may be facing serious illness & their loved ones to understand the decisions they may need to make and find resources - as early as possible!



Provide professional networking & training



Change the System - Policy & Legislation

A Movement for Change



Kōkua 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*

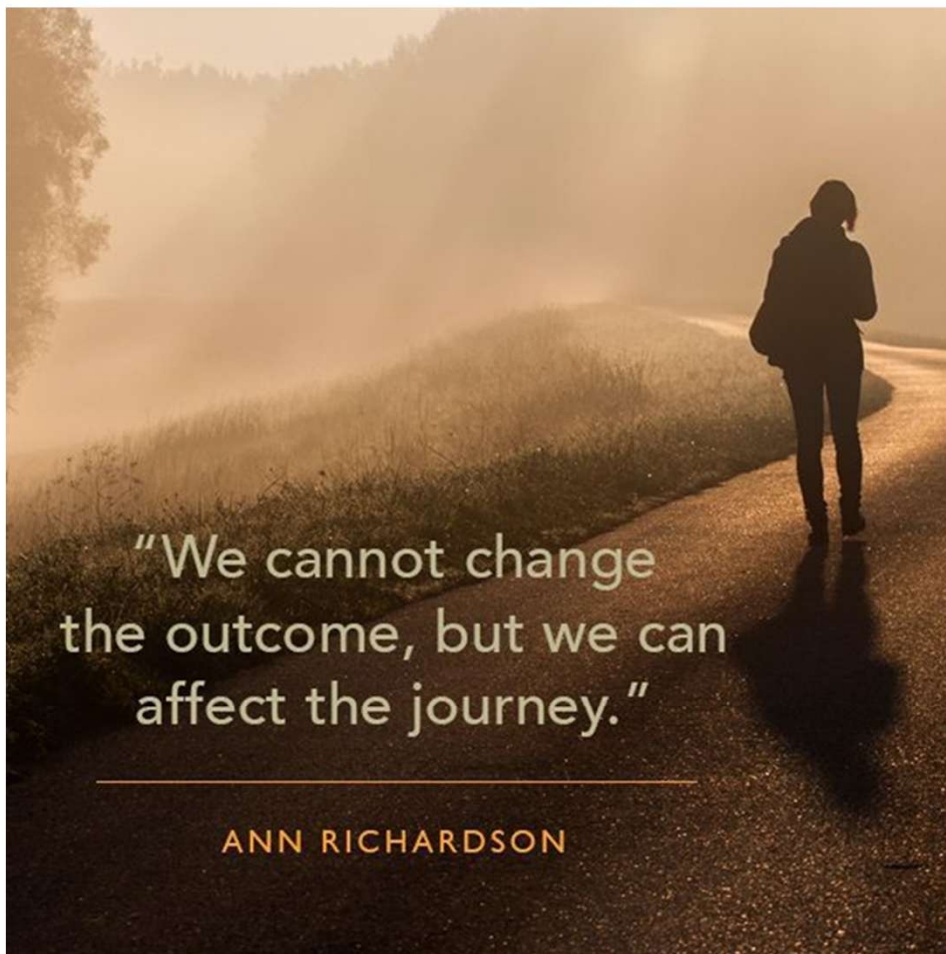


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“...modern medicine has yet to make even one person immortal. Therefore, at some point, more treatment does not equal better care.”

--Dr. Ira Byock



"We cannot change
the outcome, but we can
affect the journey."

ANN RICHARDSON



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What is 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.
- It reduces physical discomfort, improves quality of life, and makes living with a serious illness easier.
- Palliative care helps people with serious illness stay at home rather than having to go to the ER or the hospital.

What is a serious illness?

- **Cancer:** tumor or abnormal mass that grows in your body, may be spreading
- **Heart disease:** CHF (Chronic Heart Failure), heart attack, weak heart, large heart
- **Lung disease:** COPD, smoker's lung, chronic cough, lung congestion...
- **Kidney disease:** Kidney failure, Kidney dialysis, weak kidneys...
- **Liver disease:** Cirrhosis, Liver failure, yellowing of eyes/skin...
- **Diseases of the brain or nerves:** Stroke, paralysis, seizures, dementia, Parkinson's Disease...
- **And more....**



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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

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

Why Palliative Care (con't.)



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

Can be provided along with curative treatment

It's an extra layer of support for people facing a serious illness and their loved ones

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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Who is on the Palliative Care Team?

- Doctor
- Nurse
- Social Worker (LCSW)
- Grief Counselor
- Child Life Specialist (pediatric cases only)
- Optional - CNA, Pharmacist, Community Health Worker, APRN or PA, other types of nurses, licensed mental health professional



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How Does a Palliative Care Nurse Help You?

Diana, APRN



HUI POHALA



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The Perspective of a Palliative Care Social Worker

Cecilia Ortiz, LCSW



HUI POHALA



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Palliative Care gives extra support from a caring team, that helps you:



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- Spend more days comfortably at home with family and less visits to the hospital by providing support for your family, caregivers and loved ones
- Provides medical advice via phone 24/7
- Manage problems of your illness such as pain, trouble breathing and upset stomach
- By explaining care and treatment options to you and your loved ones
- Meet with your doctor so that your doctor knows what is important to you
- Connect to other resources and programs in the community

Palliative care
is care the way it should be



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How Can Palliative Care Help You?

- Eyes and ears in the home between doctor visits
- Extension to the care team already in place
- Advocate for you and your caregivers - help communicate between different providers
- Extra Support - Don't give anything up
- 24/7 Telephone Support
- At any stage of a serious illness, alongside curative treatment, palliative care can help



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Signs that Palliative Care should be considered

Frequent ER visits or calls to the doctor

Difficulty managing medications

A diagnosis of a life-long illness

Diminished activities of daily living (bathing, walking, getting out of a chair, eating, sleeping a lot)

Significant weight loss in a short amount of time

Pain, fatigue, swelling in feet & legs, nausea

Where can you find Palliative Care?

1. **Hospital In-patient** - QMC Punchbowl & West, HPH, VA, Kaiser
2. **Hospital Out-patient** - QMC Supportive Oncology Clinic, Straub Oncology, Kaiser

<https://kokuamau.org/where-to-find-palliative-care-in-hawaii/>

Ask for "a Palliative Care Consult"



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Where to find Home & Community Palliative Care

Health Plans and Agencies

- HMSA: Supportive Care
- UHA: Concurrent Care
- VA: Concurrent Care Benefit MDX - United and Humana Medicare
- MedQuest (New Benefit)
- Hawaii Care Choices (Hilo): Kupu Care
- Bristol Hospice
- Navian Hawaii - Integrated Care
- Hospice Maui
- Islands Supportive Services
- Malama Ola

<https://kokuamau.org/where-to-find-palliative-care-in-hawaii/>

Where can people get the new MedQuest Palliative Care?



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- Wherever you live or in your doctor's office
- Clinics/Office Settings
- Community Health Centers
- Assisted Living facilities
- Long-term care facilities
- Skilled nursing facilities
- Other residential settings, including foster and care homes

<https://kokuamau.org/palliative-care-services-benefit/>

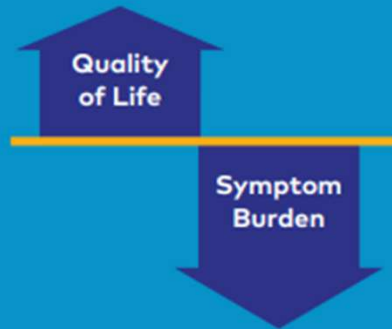
How to find out if Palliative Care can help you:

- Talk to your doctor or healthcare provider about **Palliative Care**
- Talk to the agencies that provide Palliative Care
- Visit getpalliativecare.org
- Visit <https://kokuamau.org/palliative-care-for-patients-and-families/>



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IMPROVES QUALITY OF LIFE AND SYMPTOM BURDEN



Reduces symptom
distress by

66%

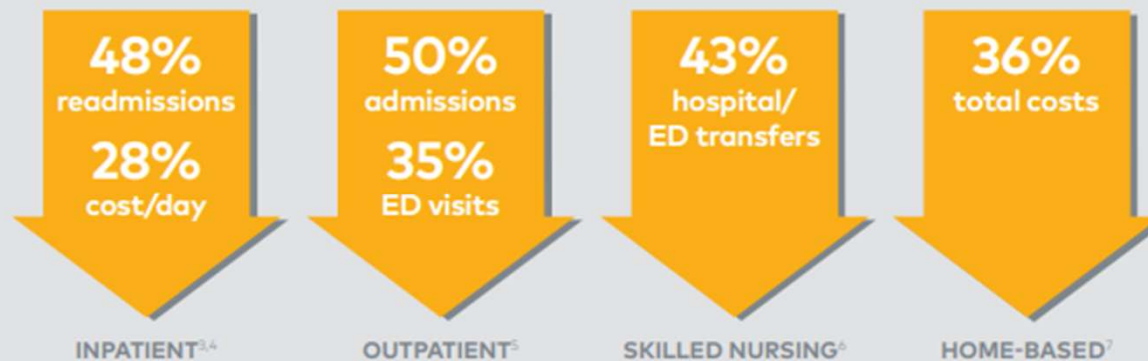
with improvements
lasting months after
initial consultation¹

DRIVES HIGH SATISFACTION AND POSITIVE PATIENT EXPERIENCES

93%

of people who received
palliative care are
likely to recommend it
to others²

REDUCES AVOIDABLE SPENDING AND UTILIZATION IN ALL SETTINGS



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Palliative Care Supports Caregivers, too!





Palliative Care helps
you
live as well as possible
for as long as possible



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Join Us at Kōkua Mau!!

Resources and other activities

- Join Kōkua Mau Mailing List
- Download materials from the Kōkua Mau Website - look for the Tool Kit
- Use the translations - 13 languages
- Request a speaker from Kōkua Mau's **Let's Talk Story** Program - We are ready to talk with your church or other group!



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Kōkua Mau Let's Talk Story Program



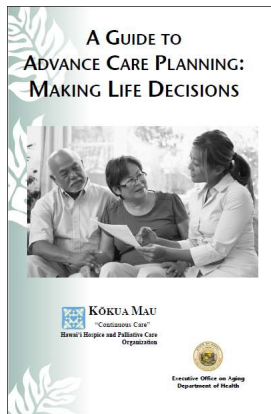
Kōkua Mau Let's Talk Story Program

- ▶ Advance Care Planning
- ▶ Conversations about wishes for care
- ▶ Documents to support wishes
- ▶ Gift to loved ones
- ▶ Where people live, work, play and pray
- ▶ Customized for the audience
- ▶ 2 sessions; opportunity to complete documents



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Kōkua Mau Resources



HAWAII ADVANCE HEALTH CARE DIRECTIVE

My name is _____ Last First Middle Initial _____ Date of Birth _____

PART I: HEALTH CARE POWER OF ATTORNEY – DESIGNATION OF AGENT.
I designate the following individual as my agent to make health care decisions for me:

Name	Relationship of individual designated to health care agent
Name Address City State Zip	
Name Address City State Zip	

PART II: MY AGENT'S AUTHORITY OR MY AGENT OR MYSELF, AS MY AGENT, DESIGNATES THE FOLLOWING INDIVIDUAL AS MY ADVISORY AGENT.

Name	Relationship of individual designated to health care agent
Name Address City State Zip	
Name Address City State Zip	

AGENT'S AUTHORITY AND OBLIGATION.
My agent's authority to make health care decisions for me is limited to the following:
☐ I grant my agent authority to make health care decisions for me in all cases.
☐ I grant my agent authority to make health care decisions for me in all cases except those that I have specifically listed below.
☐ I grant my agent authority to make health care decisions for me in all cases except those that I have specifically listed below.

PART III: INDIVIDUAL INSTRUCTIONS (You may modify or revoke these instructions at any time.)
☐ I have an incurable and irreversible condition that will result in my death within a relatively short time.
☐ I have an incurable and irreversible condition that will result in my death within a relatively short time.
☐ I have an incurable and irreversible condition that will result in my death within a relatively short time.

Questions about CPR

Being asked to make a decision about cardiopulmonary resuscitation (CPR) can be complicated. Here are some questions to help you decide what you want to do.

WHAT DOES CPR LOOK LIKE?
CPR is a longer process than most people realize. It is an attempt to restart the heart when the heart has stopped beating.

WHO IS LEAST LIKELY TO BENEFIT FROM CPR?
CPR is a longer process than most people realize. It is an attempt to restart the heart when the heart has stopped beating.

WHAT DOES CPR LOOK LIKE?
CPR is a longer process than most people realize. It is an attempt to restart the heart when the heart has stopped beating.

Tube Feeding

Being asked to make a decision about tube feeding can be complicated. Here are some questions to help you decide what you want to do.

WHAT IS A FEEDING TUBE?
Artificial nutrition and hydration is a way of giving liquid and nutrients to people who cannot eat or drink on their own.

WHO IS LEAST LIKELY TO BENEFIT FROM A FEEDING TUBE?
Artificial nutrition and hydration is a way of giving liquid and nutrients to people who cannot eat or drink on their own.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

A. CARDIOPULMONARY RESUSCITATION (CPR)
☐ I want CPR. ☐ I do not want CPR.
☐ I want CPR. ☐ I do not want CPR.

B. MEDICAL INTERVENTIONS
☐ I want medical interventions. ☐ I do not want medical interventions.
☐ I want medical interventions. ☐ I do not want medical interventions.

C. ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and liquid by mouth if feasible and desired.
☐ I want artificial nutrition. ☐ I do not want artificial nutrition.
☐ I want artificial nutrition. ☐ I do not want artificial nutrition.

D. SIGNATURES AND SUMMARY OF MEDICAL CONDITION
☐ I am a patient. ☐ I am a surrogate.
☐ I am a patient. ☐ I am a surrogate.

A Provider's Guide to POLST

What is POLST?
POLST is a document that provides information about a patient's wishes regarding life-sustaining treatment.

Why is the POLST form important?
The POLST form is a document that provides information about a patient's wishes regarding life-sustaining treatment.

How do providers get a copy of the POLST form?
Providers can get a copy of the POLST form from the patient or the patient's surrogate.

What is POLST?

Provider Orders for Life-Sustaining Treatment
A Consumer Guide to POLST

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Chinese simplified

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
Tamil 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 Hawaii
- Chinese traditional POLST Form for Hawaii
- Ilocano POLST Form for Hawaii
- Japanese POLST Form for Hawaii
- Korean POLST Form for Hawaii
- Marshallese POLST Form for Hawaii
- Spanish POLST Form for Hawaii
- Tamil POLST Form for Hawaii
- Tongan POLST Form for Hawaii
- Vietnamese POLST Form for Hawaii



<http://www.kokuamau.org/>

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Thank You!