

Kōkua Mau's Let's Talk Story Program

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*Palliative Care? Hospice Care?
What's the difference?*



KŌKUA MAU
"Continuous Care"



KŌKUA MAU
"Continuous Care"
A Movement to Improve Care

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

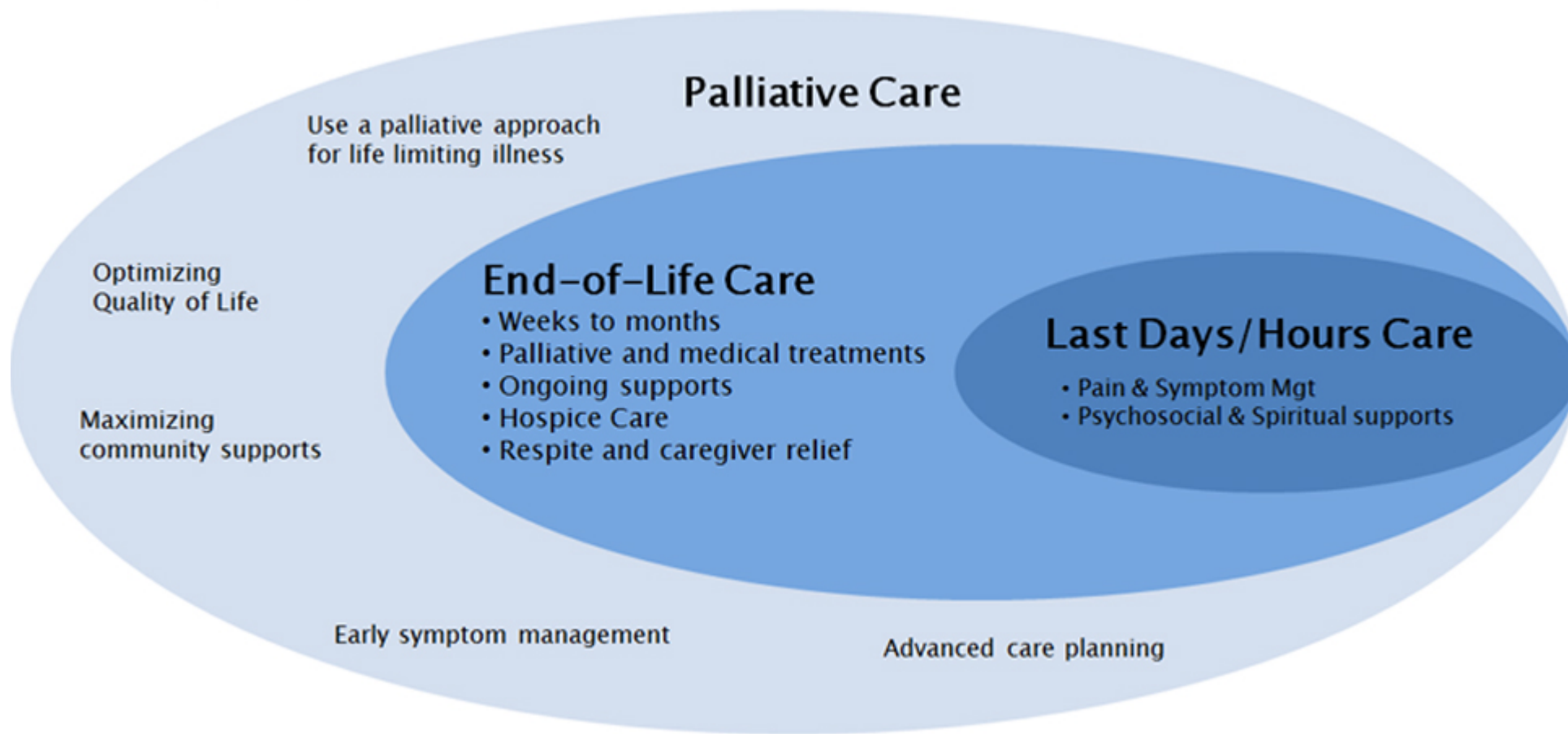
Three areas of activity

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

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*





KŌKUA MAU
“Continuous Care”

A Movement to Improve 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)

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 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

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
 - ▶ Hawaii Care Choices (Hilo): Kupu Care
 - ▶ Kauai Hospice
 - ▶ Bristol Hospice on Oahu (new program)
 - ▶ Attention Plus Home Health

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



Hospice Care

- ▶ Specialized type of care for those facing a life-limiting illness, their families and their caregivers.
- ▶ 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 end-of-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

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?
- ▶ 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?



Myths and facts about Hospice Care

Myth:

- ▶ People “go” to hospice.
- ▶ People don’t get care when they start hospice, it’s only for people ready to die
- ▶ Hospice means giving up hope, and I’m not ready to do that
- ▶ Hospice is expensive

Fact:

- ▶ Hospice is not a place; it is a philosophy of care. Hospice is usually provided in-home or wherever the individual lives
- ▶ Hospice helps to avoid unwanted treatment while supporting the individual and loved ones
- ▶ Hospice allows individuals and loved ones to live well through the end-of-life with support services in place (the mortality rate is still 100%)
- ▶ Hospice is a Medicare Benefit, most health insurances pay for hospice services

Myths and facts about Hospice Care

Myth:

- ▶ Hospice hastens death
- ▶ Once someone chooses hospice, they are not able to change their mind
- ▶ “I’m not ready to die”
- ▶ It’s too early to call in hospice

Fact:

- ▶ Studies have shown that hospice care can actually increase survival for certain diagnosis when implemented earlier during the illness
- ▶ Hospice patients maintain their autonomy and can elect to stop hospice at any time
- ▶ We will all someday die. If you have a life-limiting terminal illness or diagnosis, hospice can support individuals and their loved ones at the end-of-life and after death
- ▶ If diagnosed with a terminal illness with 6 months or less to live, it is never too early to call in hospice

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.

Facts about Hospice (con't)

10. Hospice does not make death come sooner, it can actually make people live longer!
11. Morphine prescribed to a hospice patient does not cause premature death but helps maintain Quality of life until the end of life
12. 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.

Kokua Mau Resources

A GUIDE TO ADVANCE CARE PLANNING: MAKING LIFE DECISIONS

KOKUA MAU
"Continuous Care"
Hawaii's Hospice and Palliative Care Organization

Executive Office on Aging
Department of Health

YOUR ADVANCE DIRECTIVE FOR FUTURE HEALTH CARE

HAWAII ADVANCE HEALTH CARE DIRECTIVE

My name is: _____ Form: Middle-Initial Date of Birth: _____

PART 1: HEALTH CARE POWER OF ATTORNEY - DESIGNATION OF AGENT
I designate the following individual as my agent to make health care decisions for me:

Name	and relationship of individual designated to health care agent
Street Address	City State Zip
Phone Number	Cell Home Email

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:

Name	and relationship of individual designated to health care agent
Street Address	City State Zip
Phone Number	Cell Home Email

AGENTS AUTHORITY AND OBLIGATION:
My healthcare agent should make decisions as I have instructed in Part 2 of this form or as I may otherwise provide orally or in writing. If there are no decisions for which I have provided instructions, I want my agent to make such decisions as I would have chosen to do, basing them on my values, goals, and preferences rather than those of my agent. If a plurality of my preferences are to be ascertained for me by a court, I maintain my agent.

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

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

PART 2: INDIVIDUAL INSTRUCTIONS (You may modify or strike through anything which you do not agree, initial and date any modifications.)

A. END OF LIFE DECISIONS

- I have an incurable and irreversible condition that will result in my death within a relatively short time. OR
- 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
- 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
- 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

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 limit your selection.

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

OR

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

Share and discuss your Advance Health Care Directive with your doctor, loved ones and agent. **Page 1 of 2**

Questions about CPR

Being asked to make a decision about cardiopulmonary resuscitation (CPR) can be complicated. Few of us have ever seen CPR performed. Our understanding of CPR may come from what we see on TV, where it looks easy and seems to be very successful without any complications. Unfortunately, these TV images of CPR are not completely accurate.

This brochure provides answers to some common questions about what CPR involves and what else is important to think about when making a decision about CPR.

Kokua Mau - Hawai'i Hospice and Palliative Care Organization

WHAT DOES CPR LOOK LIKE?

CPR is a longer process than most people realize. It is an attempt to re-start the heart when the heart has stopped beating.

The person is placed on a hard board or on the ground and the center of the chest is pushed about 1.5 to 2 inches. These chest compressions must be done 100 times each minute. Artificial respiration using a special mask and bag over the person's mouth to pump air into the lungs may be started when the emergency team arrives, although tubes may be inserted into the windpipe to provide oxygen, and a number of electrical shocks may be given with paddles that are placed on the chest. An intravenous line (IV) will be placed in a vein and medications will be given through the IV line.

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.

WHO IS LEAST LIKELY TO BENEFIT FROM CPR?

Risk factors that are more frequent among older persons may contribute to lower chances of CPR survival as age increases. Most older adults do not have the type of heart rhythm that responds to CPR. Having any chronic disease that affects the heart, lungs, brain or kidneys can lower chances for survival after cardiac arrest. If a person has multiple advanced chronic illnesses, CPR survival will be even lower.

Individuals in advanced stages of dementia have CPR survival rates three times lower than those without dementia. Several studies that looked at survival of frail nursing home residents in advanced stages of illness who were dependent on others for all of their care showed CPR survival rates of 0-9% even if they were transferred from the nursing home to the hospital before the cardiac arrest. Older adults in terminal stages of cancer had CPR survival rates = 1%.

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A GUIDE FOR DECISION MAKING

Tube Feeding

"I've been asked to decide about a feeding tube."

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 questions was most helpful.

HOWEVER... Every situation is different... what may help someone with a short-term comfortable eating program may not be best for long-term use for a person with advanced illness or age.

Kokua Mau - Hawai'i Hospice and Palliative Care Organization

What is a feeding tube?

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 nasogastric tube (called a nasogastric "NG" tube) is put through the person's nose and ligated through the skin into the stomach, called a gastric or "G" tube or PEG tube (Percutaneous Endoscopic Gastrostomy) or the stoma (called a stoma or "T" tube). Sometimes fluids are given through a vein (IV).

When individuals lose their ability to swallow or lose interest in eating, this often represents progression of their disease. When this happens, the body is in a natural progression toward the end of life. This normal tendency for the body not to want to eat or drink helps the body to produce its own chemicals (called endorphins) to make itself more comfortable. Sometimes an elderly individual who has not been diagnosed with a disease still begins to lose interest in eating. If the person does not seem to be depressed and there is no other physical cause, this may be a natural process sometimes referred to as "Adult Failure to Thrive."

When are feeding tubes less helpful?

Some people fear that not providing a feeding tube means they are letting their loved one "starve to death." This is not true. Starvation occurs when a person whose body needs, and can use the nutrients it depends on food. When a person's body begins to shut down, they will be physically unable to adequately use nutrients that tube feeding would provide, and the chance for bloating and discomfort increases.

continued on next page

A GUIDE FOR DECISION MAKING

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

PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

PLEASE follow these orders. They contain the patient's preferences. The physician will follow these orders to the extent of the patient's current medical condition and unless they are not medically appropriate. All treatment for heat stroke. Treatment that is approved with signed and dated orders.

A. CARDIOPULMONARY RESUSCITATION (CPR): "Person has no pulse and is not breathing"
 Attempt Resuscitation/CPR Do Not Attempt Resuscitation/DNAR (Allow-Natural Death)
 Decision B. Full Treatment required.

If this patient has a pulse, then follow orders in **B and C**.

B. MEDICAL INTERVENTIONS: "Person has pulse and/or is breathing"
 Comfort Measures Only. Use medications by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Respire 2 oxygen masks over face if ordered. Available.
 Limited Additional Interventions include care described above, the medical treatment, antibiotics, and fluids as indicated. Do not attempt. Use care as desired or only support if continued to prevent further airway emergency. Transfer to hospital if indicated. Avoid intubation.
 Full Treatment. Include care described above, the medication, advanced airway interventions, mechanical ventilation and other interventions as indicated. Provide to hospital if indicated. Intubation only.
 Additional Orders: _____

C. ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and liquid by mouth if feasible
 No artificial nutrition by tube Comfort end period of artificial nutrition by tube
 Long term artificial nutrition by tube Comfort end period of artificial nutrition by tube

D. SIGNATURES AND SUMMARY OF MEDICAL CONDITION (Discussed with patient or legally authorized representative.)
 Patient or Legally Authorized Representative (LAR) (LAR is checked, you must check one of the boxes below.)
 Guardian Agent designated in Power of Attorney for Healthcare Patient designated surrogate
 Surrogate selected by designation of interested persons (sign section 5) Parent of a Minor

Signature of Provider (Physician/APRN licensed in the state of Hawaii)
 My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.
 First Name: _____ Last Name: _____ Phone Number: _____
 Provider Signature (Printed): _____ Provider License #: _____
 Signature of Patient or Legally Authorized Representative
 My signature below indicates that I am an authorized representative consistent with my wishes or (if signed by LAR) the known wishes and/or to the best interests of the patient, which the patient or LAR has indicated.
 Signature (Printed): _____ Relationship (Printed "Sur" if patient)
 Summary of Medical Condition: _____ Date of Last Visit: _____

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

A Provider's Guide to POLST

Provider Orders for Life-Sustaining Treatment Maintained for Hawaii by Kokua 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 wishes 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 wishes 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 choice about full resuscitation or do not attempt resuscitation.

Is POLST the same as an Advance Health Care Directive?
 NO. POLST does not replace an Advance Health Care Directive (AHCD). The AHCD can provide significantly more detail about an individual's wishes and preferences for treatment. In addition, the AHCD is the most common mechanism for designating a legally authorized representative decision maker for the patient.

Will the CO-DNR bracelet still be honored by EMS?
 YES, the CO-DNR bracelet is still a valid method to communicate a person's intent about attempts to resuscitate. There are still thousands of these bracelets in use, and EMS personnel will continue to honor this directive.

Why is the POLST form lime green?
 The POLST form is usually completed on a distinctive bright lime-green form, but is also freely available from the internet (at www.kokuamau.org/polst) and is acceptable in black and white. The bright color is to make the form quickly visible to handlers and emergency medical services personnel. The lime-green color is also easily copied. A copy on white paper is a valid document.

Does the POLST form travel with the patient between settings of care?
 Yes, the POLST form is designed to be a document form that may be accepted by providers across the state. As a legal medical order, it will be honored by EMS, hospitals, long-term care facilities, home care and hospice providers may also voluntarily honor the form and include it into their medical records. However, providers with electronic medical records may choose to keep the essence of the orders into their specific system. Hospital discharge planners are encouraged to support the completion of the POLST form (when clinically appropriate) as a part of their daily practice.

Is implementing the orders from the POLST form protected under Hawaii Law?
 Yes. The law states that no provider should be held liable for criminal prosecution or civil liability for failing to follow the treatment orders in good faith or for performing cardiopulmonary resuscitation if the person performing CPR was unaware of the POLST order to not attempt resuscitation or they believed that the treatment orders (including the DNR order) had been revoked or cancelled.

How do providers get more copies of the POLST form?
 The form is available on the Kokua Mau web site: www.kokuamau.org/polst in PDF format for easy application. It is also available on the form 50 on an 8 1/2" x 11" sheet of lime colored paper. The form must have both sides copied on the front and back of the paper.

Where is the family encouraged to keep the form?
 For the patient's home, the POLST should be kept in a clearly 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.

Page 1 of 2 - A Provider's Guide to POLST - Provided by Kokua Mau, as of July 2014 at www.kokuamau.org/pressroom/polst

What is POLST?

Provider Orders for Life-Sustaining Treatment A Consumer Guide to POLST Maintained for Hawaii by Kokua Mau

POLST - Provider Orders for Life-Sustaining Treatment is your wishes carried out through:

- your medical orders, completed by a doctor or an Advanced Practice Registered Nurse (APRN)
- followed by health care providers, including Emergency Medical Services, such as Paramedics.
- Social workers, nurses and other healthcare professionals can help you fill out your own POLST form, but it MUST be signed by your physician or APRN or nurse to be valid.
- POLST contains medical orders indicating what medical care you want or don't 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 practice from the Military or VA) MUST review and sign the POLST form.
- POLST also requires your signature or that of your legal representative.

Will the CO-DNR bracelet still be honored by EMS?
 YES, the CO-DNR bracelet is still a valid method to communicate a person's intent about attempts to resuscitate. There are still thousands of these bracelets in use, and EMS personnel will continue to honor this directive.

When would I need a POLST form?
 • Whether to attempt cardiopulmonary resuscitation or not (see website for "Questions about CPR").
 • The intensity of medical care you want.
 • If you want to be hospitalized and/or under watch conditions, and
 • If you want artificial nutrition by feeding tube (see Kokua Mau website for "Tube Feeding" handout).

FREQUENTLY ASKED QUESTIONS (FAQ)

How do I get a copy of the POLST form?
 You or your provider can download a POLST form and instructions for your doctor at the Kokua Mau website (www.kokuamau.org/polst). The Kokua Mau website is the central source for POLST information for Hawaii. Most hospitals, nursing homes, home health and hospice providers as well as others in the community also have the form for you, and the provider can assist you in understanding it and filling it out. Please remember that your POLST form must be signed by your doctor or Advanced Practice Registered Nurse (APRN) to be valid.

Does the law require that a completed POLST form?
 NO. POLST is voluntary and has been available in Hawaii since July 2009. However without a POLST, Emergency Medical Services (EMS) or other healthcare providers may be required to attempt to restart your heart and breathing should they stop, even if you do not wish an attempt to be made to resuscitate you, and would prefer to die a natural death.

Where is the POLST form kept?
 If you live at home you should keep the original lime green POLST form in a location where it can easily be seen. The best place is on your refrigerator where EMS personnel will look for it first. Other visible places could be the back of the bedroom door, on a bedside table, or in your medicine cabinet. If you reside in a long-term facility, your POLST form may be kept in your medical chart along with other medical orders. A copy of your POLST form on white paper is legal.

Page 1 of 2 - A Consumer Guide to POLST - Provided by Kokua Mau, as of July 2014, at www.kokuamau.org

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 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
- **Tagalog** POLST Form for Hawaii
- **Tongan** POLST Form for Hawaii
- **Vietnamese** POLST Form for Hawaii

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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Thank You!