Kōkua Mau's Let's Talk Story Program

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

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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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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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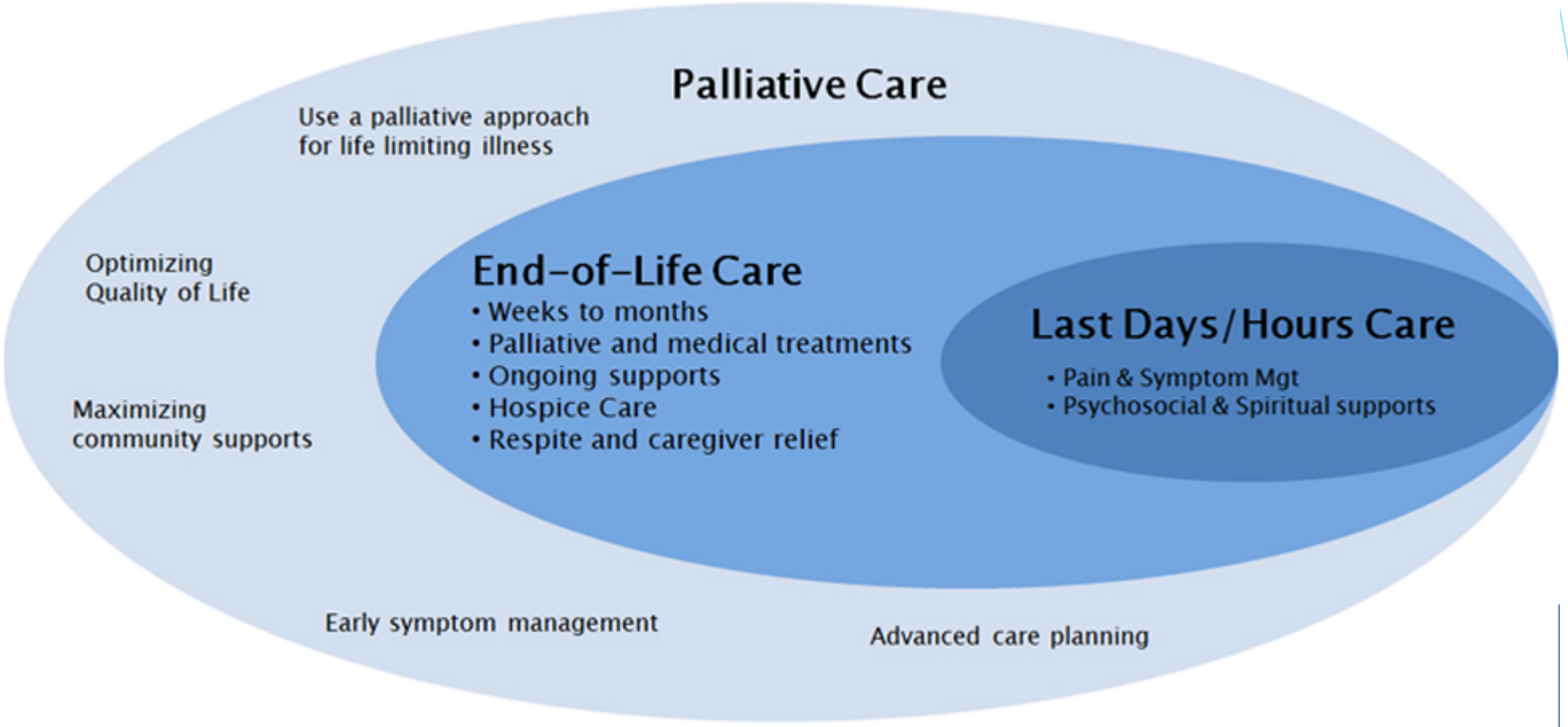

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Palliative Care

- “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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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

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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

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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.

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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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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?

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

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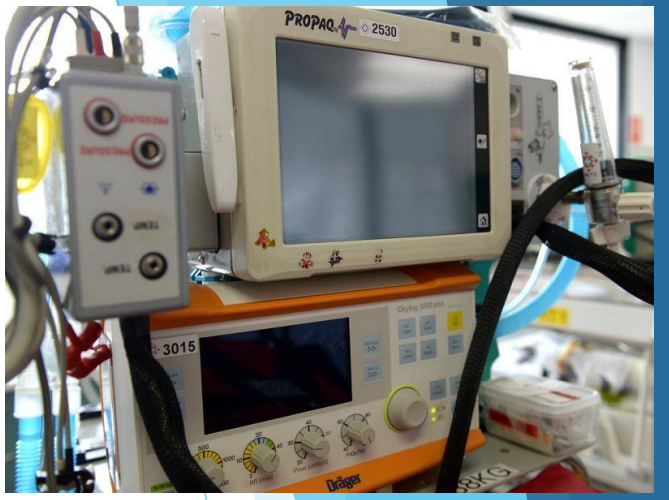
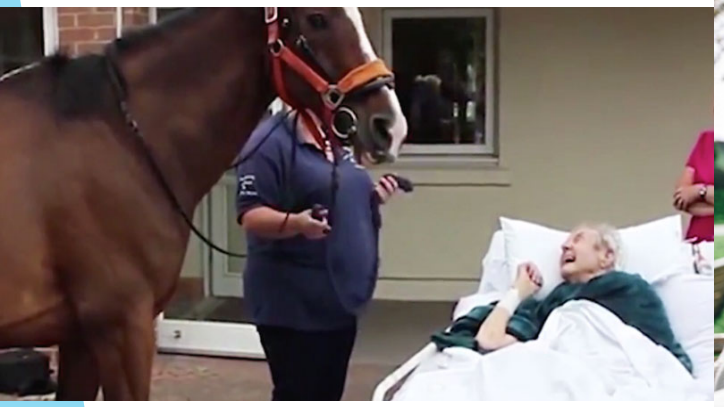


When curative treatments aren't effective and precious time could be doing and/or being with someone else, what would you choose?

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



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:	Fact:
Hospice hastens death	Studies have shown that hospice care can actually increase survival for certain diagnosis when implemented earlier during the illness
Once someone chooses hospice, they are not able to change their mind	Hospice patients maintain their autonomy and can elect to stop hospice at any time
“I’m not ready to die”	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
It’s too early to call in hospice	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.**

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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.

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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.

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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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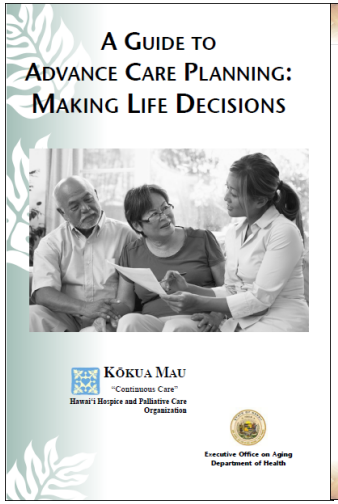
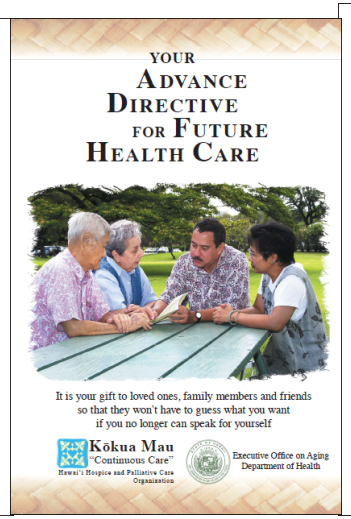
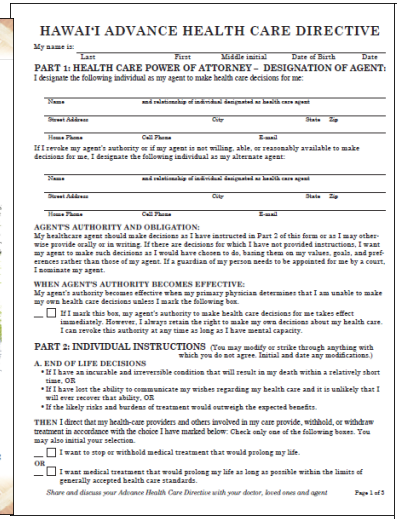
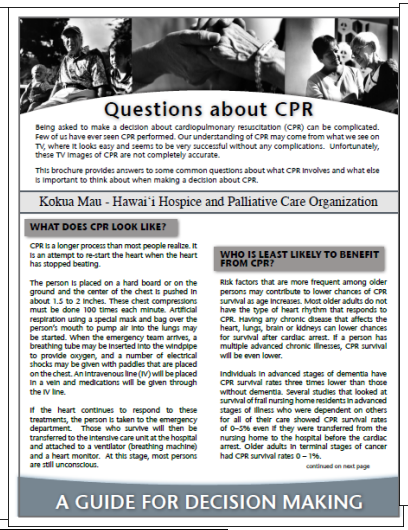
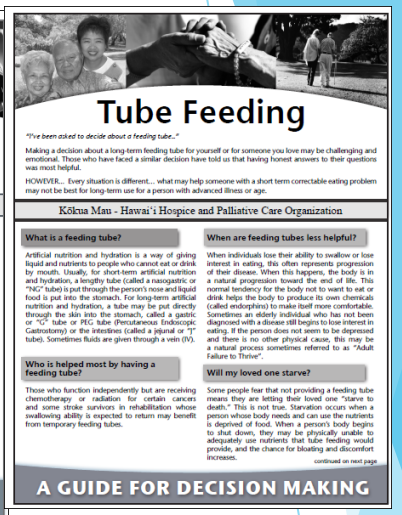
Kokua Mau Resources

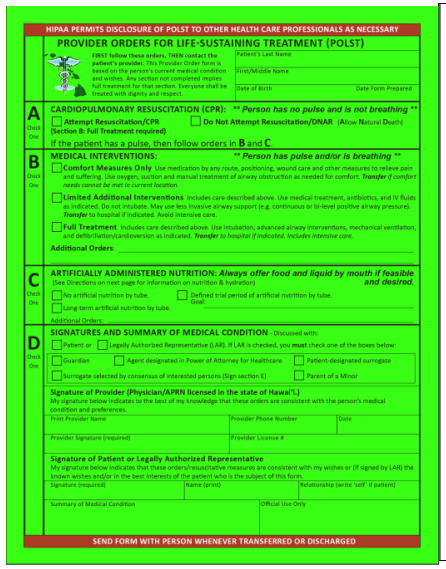


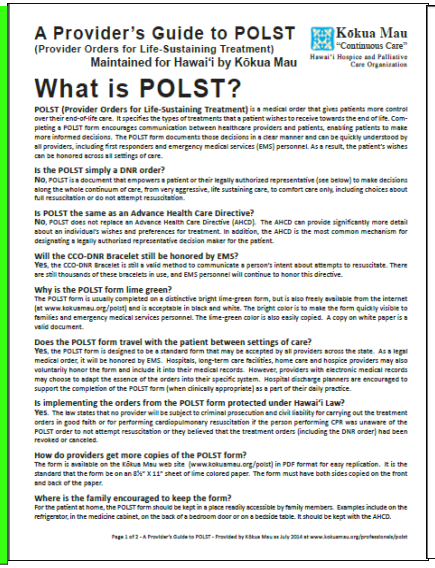


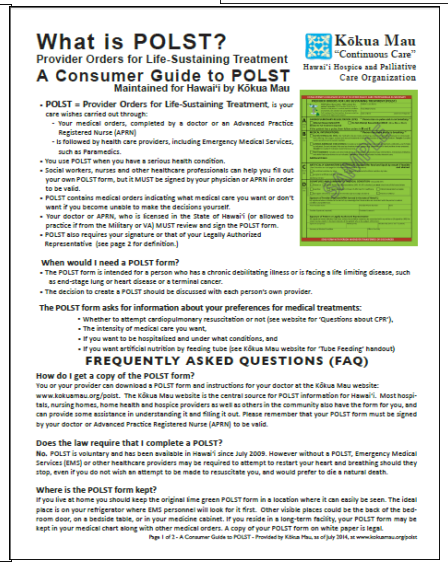












Chinese simplified Hawaii **Advance** Health Care **Directive**
Chinese traditional Hawaii **Advance** Health Care **Directive**
Ilocano Hawaii **Advance** Health Care **Directive**
Japanese Hawaii Advance Health Care Directive
Korean Hawaii **Advance** Health Care **Directive**
Marshallese Hawaii Advance 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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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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