

A GUIDE TO ADVANCE CARE PLANNING: MAKING LIFE DECISIONS



Kōkua Mau - A Movement to Improve Care

Visit www.kokuamau.org for further information and to download resources available for professionals and the general public, including Advance Directives, POLST, and local resources.



KŌKUA MAU
Continuous Care

A Movement to Improve Care



Executive Office on Aging
Department of Health

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About Kōkua Mau

Kōkua Mau is Hawai'i's Movement to Improve Care and foster conversations. We are a network whose collaborative membership includes health plans, hospice providers, hospitals, palliative care experts, long-term care providers, educational institutions and passionate community champions. We provide public and professional education, networking for professionals, and public policy and advocacy. Everyone is invited to become a member.

Kōkua Mau's vision is a community where: the people of Hawai'i are treated with dignity, compassion and love throughout their lives.

To make that vision a reality, Kōkua Mau's mission is: to weave a lei of caregiving and support so that the people of Hawai'i facing serious illness can live in the place of their choice, with relief of pain and suffering and according to their values, beliefs and traditions.

Our website www.kokuamau.org offers up-to-date information on hospice care and palliative care. It provides information and resources for people with life-threatening illnesses and their caregivers, materials for professionals, advance care planning materials (Advance Directives and POLST) and other local and national resources that can be downloaded. You can also sign up for our monthly free eNewsletter.

What is Palliative Care?

Palliative care is specialized medical care for people with serious illnesses and focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

(Center to Advance Palliative Care, 2011).

NOTE: **Bolded words** are defined on page 3 and 4.

Advance Care Planning: Making Life Decisions

This booklet is designed to help you make informed advance care planning decisions for when you are seriously ill. Many of the ideas and terms explained here might be new to you but are very common in medical settings and are important for you to know.

Although modern medicine helps many people lead longer and healthier lives, it has limits. Many of us may fear that medical technology could help us to live longer but leave us dependent on others, in pain, and unable to think or make decisions for ourselves.

We hope this booklet will help you think about these issues, come up with questions of your own, and discuss them with loved ones so that you can make good decisions about the type of care that you want for yourself or your loved ones. Once you have talked about your wishes with loved ones and your doctors, we encourage you to complete an **Advance Directive**. This form allows you to document your wishes for end-of-life care and appoint a healthcare power of attorney (sometimes called an 'agent') if you cannot speak for yourself. Please share copies with your doctors, loved ones, family members and healthcare power of attorney.

Additionally we encourage all people with serious illness to learn about **POLST** (Provider Orders for Life-Sustaining Treatment.) POLST makes your wishes known and is followed by health care professionals, including ambulance personnel. A POLST form must be signed by a physician or an advanced practice registered nurse (APRN) licensed in the State of Hawai'i (or allowed to practice if from the Military or VA) to be valid. POLST makes your wishes for healthcare known to all providers if you cannot speak for yourself. In comparison to an **Advance Directive**, it can be honored by emergency medical services. Wishes documented in a POLST can be honored across all care settings throughout the state.

You can download **Advance Directive** and **POLST** forms, as well as more information about them, from the Kōkua Mau website: www.kokuamau.org or in the mail by calling Kōkua Mau at 808-585-9977.

www.kokuamau.org/advance-directives
www.kokuamau.org/polst

Important Words to Know

Advance Directive: A set of instructions, usually written, that allows you to specify the kind of treatment you would want if you are ill and unable to speak for yourself. Both the “living will” and a “Durable Healthcare Power of Attorney” are Advance Directives and we recommend people have both. You should tell your doctors, loved ones and healthcare agent what your wishes are. You may change your Advance Directives at any time. Only you can change your Advance Directive.

Aggressive Medical Treatment: A range of treatments that use complex, invasive methods to prolong a person’s life, such as CPR, ventilation, or dialysis. Commonly asked in end-of-life situations: “Shall we continue aggressive treatments or shall we change to comfort care?”

Airway Intubation: Putting a tube through the mouth and into the lungs to get oxygen into the person’s lungs.

Allow Natural Death: Allowing a natural death simply means not interfering with the natural dying process while providing care directed at keeping someone as comfortable as possible.

Artificial Nutrition & Hydration: Artificial nutrition and hydration is a way of giving liquid and nutrients to people **through a tube** who cannot eat or drink by mouth. It can be used for a short or long period of time.

Cardiac Arrest: No effective heartbeat.

Cardiopulmonary Resuscitation (CPR): Efforts to restart breathing and heartbeat to a person in cardiac or respiratory arrest. (See p. 9)

Comfort Care: The goal of comfort care is to improve the quality of life of seriously ill people and their loved ones. The person is kept comfortable by controlling pain and other sources of distress. (See p. 6)

Diagnosis: Identification of a disease or condition from its signs and symptoms.

Durable Healthcare Power of Attorney: Allows you to name an agent to speak for you in medical matters if you cannot speak for yourself either because of illness or an accident. Your agent should know your wishes and agree to follow them. This is one type of an **Advance Directive**.

Dialysis: Removal of waste, salts, and extra liquid from blood by artificial means when the kidneys fail. (See p. 11)

More on the website: www.kokuamau.org/resources/definitions

What is Hospice Care?

Hospice is a special kind of care helping those with a life-limiting illness, with a prognosis of six months or less, live with dignity and comfort, either at home or in an inpatient care setting. It is a philosophy of care that goes beyond the cure, offering the services of an Interdisciplinary Team consisting of a physician, nurses, nurse-aides, social workers, spiritual counselors, nutritional and other therapists, and specially trained patient-care volunteers, focusing on the whole person; mind, body and spirit. Most hospice programs are funded through reimbursements from their patients' health insurance plans (e.g. Medicare, Medicaid and private insurance). In cases where there is no insurance coverage, most hospice programs will provide core services at no cost. (See page 15).

Intravenous (IV): A small plastic tube (catheter) is inserted directly into the vein and fluids are administered through the tube.

Living Will: A document regarding your wishes for medical treatment when you are in imminent danger of dying, including artificial nutrition and hydration. This is one type of **Advance Directive**.

Mechanical Ventilation: Use of an artificial breathing machine (respirator or ventilator) to maintain breathing by a tube placed into the windpipe. It is different than the much less invasive use of oxygen delivered by a nasal device or mask. (See p. 10)

Palliative Care: See box on Page 1.

Prognosis: Prediction; the likely outcome or result of a disease or medical condition.

POLST: Provider Orders for Life-Sustaining Treatment is a form that contains specific medical orders that specify the type of care you would like in the event of a health emergency. This form can be quickly understood and honored by all health care professionals including first responders and ambulance personnel.

Respiratory Arrest: Unable to breathe on one's own

Symptom Management: Treating physical problems such as pain, nausea, depression or anxiety. It can be done with or without treating the underlying cause of the sickness. For example, a person receiving comfort care for an incurable cancer can have the symptoms managed without further treating the cancer itself.

Terminal condition: An incurable or irreversible disease or condition for which medical treatment may extend life but cannot prevent death.

Promoting Better Communication and Shared Decision-Making

Doctors may be your first source for information about medical conditions and treatment choices. Be sure to ask questions, especially if there are things you don't understand. You have the right to ask questions and to expect honest and thoughtful answers. However, many doctors have been trained to give only facts, not guidance, and may not be comfortable making recommendations. Many doctors prefer to present facts and options, encouraging people to make their own decisions.

Other healthcare workers, like nurses, social workers, and chaplains, are trained to talk with you and your loved ones about your wishes, hopes, and fears at the end of life. They can help explain the choices you have in making decisions and can talk about your goals for treatment and care. These include your quality of life, keeping your independence, being free of emotional and physical distress, and treating illness. These people may be the first to see that a change in your treatment and goals is needed.

Last, but not least, family, loved ones, and spiritual leaders all bring important but different viewpoints.

Talking things over with all these individuals can help you in making hard decisions.

Questions

- What is the **prognosis** for my condition, and what are my choices?
- What will my life be like with **aggressive medical treatments**, and do I want to live like that?
- How have other people coped with this?
- Who else can I talk to?
- How do I find the people to talk to about my situation?
- What kind of end-of-life care, including hospice, is available in my community?

- What does dying mean to me and my loved ones?
- What will help me and my loved ones feel at peace?
- How does my family feel about my wishes?
- What are the costs of these treatments?
- What costs will my health insurance cover?
- What personal, legal and business matters need to be taken care of?

What is Comfort Care?

Kōkua Mau believes that care when you are seriously ill should be compassionate and should help with your emotional and spiritual needs, as well as controlling pain and treating physical problems (such as shortness of breath, constipation, nausea or skin problems).

The goal of comfort care is to give the best quality of life for the person and family during the time of illness, dying, and grieving.

If your goal is quality of life, comfort care can help you and your loved ones. It can be added to your medical care plan early in the course of serious illness rather than waiting until the very end. As part of your medical care plan you may also be making decisions about **CPR**, **artificial nutrition** and **hydration**, and **dialysis**. These topics and others are described in this brochure. Comfort care does not mean “no treatment”.

Questions

- How can I get comfort care?
- When should I begin comfort care?
- Who offers comfort care?
- What will comfort care give me?
- Will I still get any medications for pain?
- Will I be able to stay at home?

Medical Conditions Associated with Serious Illness

Despite medical advances, the goals of medicine - curing disease, restoring health, and relieving symptoms - do not always happen. People with the following conditions may be kept alive for months and years by machines and measures that extend life, but will never get well. While comfort care may not extend life, the quality of life is improved to the best extent possible and is a choice you may want to discuss with your doctor.

Advanced Cancer

Common problems in people with advanced cancer include nausea, weakness, weight loss, pain, and breathlessness.

Advanced Heart or Lung Disease

Over time such conditions progress to the point that a person with chronic lung disease becomes dependent on oxygen for minimal physical activity or even rest. Shortness of breath becomes nearly constant with difficulty talking, swallowing, and sleeping. Failure of the heart also results in shortness of breath, inability to perform physical activities, and fluid retention.

Dementia

Dementias such as Alzheimer's Disease involve a slow and permanent loss of mental abilities, such as talking, making decisions, and thinking. In end-stage dementia, people are completely dependent on others. They become unable to speak, walk, or move and unable to control bowel and bladder functions; they have less appetite and trouble swallowing and eating and they do not recognize loved ones.

Persistent Vegetative State (PVS)

People with PVS are not aware and cannot interact with the world around them. People may have open eyes, yawn and appear to sleep but they have very little brain activity and are capable only of involuntary and reflex movements. To confirm someone has PVS requires many tests that take several months. Unlike people with other types of coma, persons in PVS never become aware or get better. People in PVS have no awareness of hunger, thirst, or pain.

Questions

- What will **comfort care** offer in these conditions?
- Would I want life support to extend my life under these conditions?
- Who should I talk to about my wishes?
- What are the benefits and problems of aggressive medical procedures for people with these conditions?
- How do I know when **comfort care** is better than aggressive medical treatments?

Medical Technologies

Medical technologies that may be used include:

- **Cardiopulmonary resuscitation (CPR)**
- **Mechanical ventilation**
- **Dialysis**
- **Artificial nutrition and hydration**

Each of these methods is described so that you can better understand what they mean. Any of these can be useful in some cases and not in others – it depends on the person’s wishes, the benefits or problems with the procedure, and the person’s medical **prognosis**.

We urge you to carefully think about whether or not these medical treatments may be right for you or your loved one.

Please refer to the sheets "Tube Feeding" and "Questions about CPR" on our website: www.kokuamau.org/tube-feeding & www.kokuamau.org/cpr

“How people die remains in the memory of those who live on.”

Dame Cicely Saunders
Founder of the Modern Hospice Movement

What is CPR?

Cardiopulmonary resuscitation (CPR) is a longer process than most people realize. It is an attempt to re-start the heart when the heart has stopped beating. CPR involves pushing on the chest and sometimes artificial breathing for someone who is having a cardiac or respiratory arrest. CPR typically also includes a breathing tube inserted into the windpipe to provide oxygen, and a number of electrical shocks may be given with pads that are placed on the chest. An **intravenous** line (IV) may be placed in a vein and medications will be given through the IV line.

The success of CPR depends on the reason the heart stopped, how healthy the person was before the heart stopped and how long the heart has been stopped before CPR was started. In some cases CPR is successful, but it is also possible for someone to suffer brain damage and become even more ill and dependent on medical technology following CPR.

Risk factors that are more frequent among older persons may contribute to lower chances of CPR survival as age increases.

In Hawai'i, if you do not want CPR at the end of life:

- Discuss your wishes with your doctor and family and document them in your **Advance Directive**.
- Provide a copy of your Advance Directive to your doctors, loved ones, family and caregivers. Make sure to take a copy with you when visiting doctors and hospitals and ask to have it added into the Electronic Medical Record (EMR).
- Complete a **POLST** document with your physician or an advanced practice registered nurse (ARNP). POLST became available in Hawai'i in 2009. It is a form that contains specific medical orders that specify the type of care you would like in the event of a health emergency. This form can be quickly understood and honored by all health care professionals including first responders and ambulance personnel. It can cover more aspects of your wishes.

The probability of an elderly, frail, nursing home resident surviving CPR is approximately 1% and certainly no greater than 5%.

– Zweig S, Bioethics Forum 1998: 14(1) Spring

What is Mechanical Ventilation?

Often people who are revived by CPR must use mechanical ventilation to keep on breathing. When mechanical ventilation is used, a machine called a ventilator (or a respirator) is used to take over breathing for a person who cannot breathe naturally. It is important to understand that a ventilator is not a cure in itself; it may only “buy time” to see if the person can start natural breathing again.

The benefits of using a ventilator include the following:

- Mechanical ventilation can save lives when used for people recovering from a short-term illness or accident.
- During surgery, mechanical ventilation is used for people who have been given a general anesthetic, and the ventilator keeps them breathing.

The problems of using a ventilator include the following:

- Mechanical ventilation cannot restore a person’s lungs; it cannot prevent the death of a person with an incurable, fatal disease or condition; and it cannot cure a permanent coma.
- People on mechanical ventilators need ongoing medical care, and often suffer from discomfort and complications such as pneumonia.

5 things to say to someone who is dying

- Please forgive me
 - I forgive you
 - Thank you
 - I love you
 - Goodbye
-

What is Dialysis?

Kidneys are organs that filter and clean our blood. When kidneys fail, waste and excess fluid build up in the blood. If you want to live beyond kidney failure without a kidney transplant, the work of the kidneys must be done by a treatment called dialysis. There are two kinds of dialysis:

Hemodialysis: Blood is removed through a needle in your blood vessel to be cleaned through an outside filter. People usually need several hemodialysis sessions a week, each lasting several hours.

Peritoneal dialysis: A special fluid is placed in the tummy, in the space between the intestines and the tummy wall. The fluid pulls wastes out of the blood through the membrane that lines that space, then fluid and wastes are drained out. This type of dialysis is done daily.

Using dialysis can often extend a person's life. However, problems and infections can occur. Long-term dialysis often must be continued for the rest of the person's life unless a kidney transplant is performed. Dialysis requires a strong, ongoing commitment from people, their families, doctors, healthcare providers, and support staff. It is not a 'cure' for kidney disease; it is only a partial substitute for normal kidney function.

When kidneys fail because of a **terminal condition**, dialysis will only prolong the dying process.

You can choose to forego dialysis if the short-term life prolonging benefits are outweighed by pain, suffering or poor quality of life. It is not medically recommended to begin or continue long-term dialysis in those in a persistent vegetative state, severe, progressive, irreversible diseases like Alzheimer's.

Questions

- Am I likely to need dialysis?
- Would it be long or short term?
- What are its benefits and problems?

What is Artificial Nutrition and Hydration?

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 tube (called a nasogastric or “NG” tube) is put through the person’s nose into the stomach. For long-term artificial nutrition and hydration, a tube may be put directly through the skin into the stomach, called a gastric or “G” tube or PEG tube (Percutaneous Endoscopic Gastrostomy), or the intestines (called a jejunal or “J” tube.)

Another form of long-term artificial feeding is “total parenteral nutrition” (TPN). Liquid nutrients are given through a small plastic tube (catheter) that goes directly into a large vein near the person’s heart. Sometimes fluids are given through a vein (IV).

Using artificial nutrition and hydration can often extend a person’s life. However, some of these techniques can be very uncomfortable and may increase the risk of infection and other problems.

It is often assumed that using artificial nutrition and hydration can extend a person’s life. Short-term artificial nutrition and hydration can help a person through recovery after surgery and severe injury or illness. However, in people with severe, chronic, and terminal illness, artificial nutrition and hydration is rarely beneficial and often prolongs dying. Difficulties swallowing, lack of thirst and poor appetite are natural in those declining from a serious illness. Artificial nutrition and hydration may increase discomfort by causing fluid retention and also increases the risk of problems such as infections.

Once artificial nutrition and hydration are started, it may be very difficult to stop these treatments, and to allow a person to die comfortably and peacefully.

Questions

- Is artificial nutrition and hydration an option? For how long?
- How and when should we re-evaluate whether to continue artificial nutrition and hydration?
- What are its benefits and problems?
- Would my loved one want artificial nutrition and hydration in the present situation?

Other Life-prolonging Treatments

Antibiotics

Antibiotics are commonly given to treat infections. However, the use of antibiotics should be carefully considered in terminal conditions when infections happen as a complication of the underlying incurable disease. In such cases, antibiotics can cause more harm than good or simply prolong the dying. Ask your doctor about the risks and benefits.

Blood Transfusion

Transfusions include whole blood or blood products. There comes a point at which blood transfusions no longer improve the quality of a terminally ill person's life. Transfusions can be uncomfortable, especially for people with fragile skin and veins.

Radiation

Radiation is often used in persons with cancer. The use of radiation or radioactive material can be helpful in controlling the cancer or its complications such as bone pain. Some side effects of radiation can be immediate, some happen after weeks or months. Swelling and inflammation around the site receiving radiation are common. In addition, treatment often requires many trips to the treatment center. Careful consideration should be given for people with a terminal illness.

Surgery

Before surgery is considered, you should understand the purpose, and risks and benefits of the surgery. Surgery is sometimes done to control a disease, while other times to reduce pain and increase comfort (palliative surgery).

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National Web Sites

Caring Connections - National resources and materials including pain management: www.caringinfo.org

The Metta Institute: www.mettainstitute.org

The Conversation Project: www.theconversationproject.org

The National POLST Paradigm: www.polst.org

The National Alliance for Caregiving: www.caregiving.org

Hospice:

National Hospice and Palliative Care Organization: www.nhpco.org

Palliative Care:

American Academy of Hospice and Palliative Medicine: aahpm.org

Center to Advance Palliative Care: www.getpalliativecare.org

Executive Office on Aging (EOA), State of Hawai'i

If you have questions about aging and disability, The Aging and Disability Resource Center (ADRC) is your source in Hawai'i for answers, with information about the home and community services you may need.

ADRC is a one-stop resource for long-term care, information and services. Call statewide at 808-643-2372, or visit www.HawaiiADRC.org.

The service is free.

County Offices on Aging

Honolulu Elderly Affairs Division: 808-768-7700

Office on Aging - County of Maui: 808-270-7774

County of Kaua'i Agency on Elderly Affairs: 808-241-4470

Hawai'i County Office of Aging: Hilo Office: 808-961-8626

Kona Office: 808-323-4390

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Visit www.kokuamau.org for further information and to download resources available for professionals and the general public, including Advance Directives, POLST, and local resources.

Free Speakers Bureau: Kōkua Mau wants to get our community talking about wishes for care at the end of life. Our **Let's Talk Story Program** will go out to where people work, live and pray for interactive sessions facilitated by our trained experts. To book a free workshop on this important topic, contact us at speaker@kokuamau.org or call us.

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Palliative Care is sometimes referred to as **Supportive or Concurrent Care**, and provides strong support for individuals and their loved ones with a serious illness or condition, or have complex health issues. It is not the same as hospice care, and individuals using this benefit can continue to receive curative treatments as desired. Comfort-directed services are focused to help people manage the symptoms and stresses of serious illness. Contact your health plan for further details on this beneficial service. All hospice providers offer **Community-Based Palliative Care**. Contact your preferred hospice directly.

RESOURCES YOU CAN USE: Hospice Care

Hawai'i:	Hawai'i Care Choices	808-969-1733
	Hospice of Kona	808-324-7700
	North Hawaii Hospice	808-885-7547
Kaua'i:	Kaua'i Hospice	808-245-7277
Maui:	Hospice Maui	808-244-5555
	Islands Hospice Home, Kahului	808-856-8989
Lana'i:	Hospice Hawai'i-Lana'i	808-565-6777
Moloka'i:	Hospice Hawai'i-Moloka'i	808-553-4310
O'ahu:	Bristol Hospice	808-536-8012
	Hospice Hawai'i	808-924-9255
	Islands Hospice	808-550-2552
	Malama Ola Health Services	808-543-1188
	St. Francis Hospice	808-547-6500
	Veterans Administration	808-433-7676

Hospital-based (Inpatient) Palliative Care Programs

Castle Medical Center	808-263-5253
Kaiser Permanente	808-432-7100
Kapi'olani Medical Center for Women & Children	808-983-6090
Maui Memorial Medical Ctr, Palliative Care Coordinator	808-442-5801
North Hawaii Community Hospital	808-885-4444
Pali Momi Medical Center	808-485-4545
Straub Hospital and Clinic	808-522-4000
The Queen's Health System	808-691-4726
Wilcox Memorial Hospital	808-245-1523

Community-Based (Outpatient) Palliative Care Programs

HMSA Case Management Program	1-844-378-9997	808-948-5377
Kaiser Permanente		808-432-8046
Kupu Care by Hawaii Care Choices (Hilo)		808-934-2913
Kōkua Kalihi Valley Home-Based Palliative Care Services		808-791-9410
Palliative Medicine Partners, (Kaua'i)		808-245-7277
St. Francis Supportive Care (O'ahu)		808-595-7566
UHA Comfort Care	800-458-4600 #300	808-532-4006