National Web Sites

Caring Connections - National resources and materials including pain management: www.caringinfo.org
The Conversation Project: theconversationproject.org
National POLST Collaborative: www.polst.org
The National Alliance for Caregiving: www.caregiving.org

Hospice:

Hospice Foundation of America: hospicefoundation.org

Palliative Care:

Palliative Care for Patients and Families (Kōkua Mau):
https://kokuamau.org/palliative-care-for-patients-and-families/
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

Kōkua Mau - A Movement to Improve Care

Visit **kokuamau.org** for further information and to download resources available for the general public and professionals, including multilingual Advance Directives, POLST, and many 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: speaker@kokuamau.org.

Kōkua Mau
PO Box 62155
Honolulu HI 96839

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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 multilingual Advance Directives, POLST, and local resources.

Kōkua Mau
Continuous Care
A Movement to Improve Care

June 2026

Executive Office on Aging
Department of Health

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, longterm 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 palliative care and hospice 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. You can download multilingual Advance Directive and POLST forms, as well as more information about them, from the Kōkua Mau website: kokuamau.org/advance-directives & www.kokuamau.org/polst

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)

Advance Care Planning: Making Life Decisions

This booklet is designed to help you make informed advance care planning decisions if you should become seriously ill or if the unexpected happened. 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.

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 appoint a **Healthcare Power of Attorney** (sometimes called a 'healthcare agent') if you cannot speak for yourself and document your wishes for end-of-life care. Please share copies with your doctors, loved ones, family members and your chosen Healthcare Power of Attorney.

Advance Care Planning means making a plan for your health care in case you get very sick or have an accident and cannot make decisions for yourself. All adults over 18 should think about this so their wishes are known. It is important to pick someone you trust, called a Health Care Agent or Health Care Power of Attorney, who can make choices for you if you can't. Writing down your wishes and choosing your agent helps make sure you get the care you want. Even though modern medicine helps many people live longer and healthier lives, it can't fix everything. Some of us might worry that medical machines can help us live longer, but might leave us needing help from others, feeling pain, or unable to think or make choices for ourselves.

Additionally we encourage all people with a serious illness to learn about **POLST** (Provider Orders for Life-Sustaining Treatment). POLST is an out-of-hospital medical order that makes your wishes known in case of an emergency or if you cannot speak for yourself. It is followed by health care professionals including first responders in all care settings throughout the state. A POLST form should be discussed with your care team to document your "right now" care plan. To be valid, it must be signed by a Physician, Advance Practice Registered Nurse (APRN) or a Physician Assistant (PA) licensed in the state of Hawai'i (or allowed to practice if from the military or VA.)

POLST is different than an Advance Directive. Remember: Everyone needs an Advance Directive, but not everyone needs a POLST.

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

Important Words to Know

Advance Directive: Is a legal document and is a set of written instructions that allows you to specify the kind of treatment you would want if you were ill and unable to speak for yourself. It appoints your Healthcare Power of Attorney, also referred to as your Healthcare Agent. An Advance Directive also gives directions for your agent to help with healthcare decisions to honor and support your wishes for care. You should tell your doctors and loved ones what your wishes are and who you trust to be your agent and make sure it is added to your medical record. You may change your Advance Directive 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-focused 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. *See CPR

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. Short-term Artificial Nutrition involves placing a tube up the nose, down the throat and into the belly, where nutrition is provided through the tube. Long-term Artificial Nutrition often involves an operation where a tube provides nutrition directly to the stomach.

Cardiac Arrest: A cardiac arrest is when the heart suddenly stops beating, so blood isn't pumped to the body. This is often called a heart attack. (See p. 9)

Comfort-focused Care: The goal of comfort-focused care is to proactively manage symptoms and problems to keep patients comfortable in the place they call home.

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

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

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 person is often named in an **Advance Directive**.

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

Hospice Care: See box on Page 6

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 a type of **Advance Directive**.

Mechanical Ventilation: Use of an artificial breathing machine (respirator or ventilator) to maintain breathing by a tube placed into the wind-pipe. 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: A healthcare provider's best guess about what will happen with a disease or health problem in the future.

POLST: (Provider Orders for Life-Sustaining Treatment) is a portable, out-of-hospital medical order for people with serious illness that documents the type of care you would like in the event of a health emergency and takes effect as soon as it is signed. Think of it as documenting "right now" medical orders. It must be completed with a provider to be valid. 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: Helping with physical problems like pain, feeling sick to your stomach, feeling sad, or feeling worried. You can get help with these symptoms even if doctors are not trying to cure the sickness itself. For example, someone with incurable cancer can get help to feel better, even if the cancer is not being treated anymore.

Terminal condition: A sickness or health problem that cannot be cured or fixed. Doctors might be able to help you live longer, but they cannot stop you from dying.

Promoting Better Communication and Shared Decision-Making

Doctors are usually the first people you talk to about your sickness and what treatments you can choose. It's important to ask questions if something doesn't make sense. You have the right to ask anything and expect clear, honest answers. However, many doctors have been trained to only tell you the facts and may not be comfortable to give advice about what to do. Many doctors like to share information and encourage you to decide what is best for you.

Others in healthcare, like nurses, social workers, and chaplains, are trained to talk with you and your loved ones about your wishes, hopes and fears if you are very sick. They can help you understand your choices and talk about your goals for care, like feeling comfortable, keeping your independence, and handling emotions and pain. These people are sometimes the first to notice when your care or goals need to change.

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

Talking things over with all these people can help you make important 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 do I find 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 will my family and loved ones 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 Palliative Care?

Care when you are seriously ill should be compassionate. Care 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 palliative care is to give the best quality of life for the person and family during the time of illness. Hospice Care is a type of palliative care for those in the last six months of life which supports patients, families and loved ones during the dying and grieving process.

If your goal is quality of life, palliative 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. Palliative care does not mean "no treatment".

Questions

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

What is Hospice Care?

Hospice is a special type of palliative care for people who have a serious illness and are expected to live six months or less. Hospice helps people feel comfortable and live with dignity, either at home or in another care setting. It does not try to cure the illness but instead focuses on making life better. A team made up of doctors, nurses, helpers, social workers, spiritual counselors, nutrition experts, therapists, and volunteers work together to care for the whole person, their loved ones and family - body, mind, and spirit. Usually, hospice is paid for by health insurance, like Medicare, Medicaid, or private insurance. If someone does not have insurance, most hospice programs might still provide this important care for free.

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 be cured or get better. 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

As time goes on, these illnesses can get worse. A person with chronic lung disease may need oxygen just to do simple things or even to rest. It can become hard to breathe all the time, and talking, eating, and sleeping may be difficult. If the heart fails, it also causes trouble breathing, makes it hard to do things, and can lead to swelling from extra fluid in the body.

Dementia

Dementias like Alzheimer's Disease make a person slowly lose their ability to think, talk, and make decisions for themselves. This loss does not get better. In the final stage, people with dementia need help with everything. They cannot speak, walk, or move on their own. They cannot control when they go to the bathroom. They often have less appetite and have trouble swallowing and eating. They may not know who their loved ones are. Even though dementia gets worse over time, people can live for many years with the disease.

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 **palliative 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 **hospice care** is better than aggressive medical treatments?

Medical Technologies

Medical technologies that may be used include:

- **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 giving breaths if they are not breathing. CPR often uses a tube to help the person breathe and special pads to give electric shocks to the chest. Doctors might also put a needle in a vein to give medicine to help restart the heart.

CPR does not always work. It depends on why the heart stopped, how healthy the person was before, and how quickly CPR started. Sometimes, CPR helps and the person gets better. Other times, the person might have brain damage or need more help from machines to stay alive after CPR.

Older people have more risks, and CPR is less likely to work as people get older.

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

- Talk with your doctor and family about what you want if you get very sick and write it down in your Advance Directive, so your loved ones know what care you want.
- 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 form with your physician, Advanced Practice Registered Nurse (ARPN), or Physician Assistant (PA). POLST 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, including if you do not want CPR at the end of your life.

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?

People who are revived from CPR often require 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 certain surgeries, mechanical ventilation can temporarily help the patient with breathing while under anesthesia.

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.

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:

Dialysis: Removal of waste, salt, and extra liquid from blood by artificial means when the kidneys fail

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.

Dialysis can help people live longer when their kidneys stop working. But sometimes, it can cause problems and infections. If someone doesn't get a kidney transplant, they usually have to keep getting dialysis for the rest of their life. Dialysis is not a cure for kidney disease—it just helps do some of the work that kidneys normally do. People, their families, doctors, and nurses all must work together and stay committed to helping keep the person healthy.

If your kidneys stop working because you have a serious illness that cannot be cured, dialysis will not make you better. It will only help you live a little longer, but it cannot stop the illness or make it go away.

You can decide not to have dialysis if it causes too much pain, discomfort, or makes your life harder instead of better. If someone is in a coma that won't get better or has a very serious disease that can't be cured, like Alzheimer's, doctors usually do not suggest starting or continuing dialysis for a long time.

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?

People often think that using artificial nutrition and hydration—feeding or giving fluids through tubes—can help someone live longer. Short-term use can help people recover after surgery, a bad injury, or illness. But for people who are very sick for a long time or have a serious illness that cannot be cured, artificial nutrition and hydration usually does not help much and may only make the dying process last longer. When someone is very sick, it is normal for them to have trouble swallowing, not feel thirsty, and have a poor appetite. Giving food or fluids through tubes may make them feel worse by causing their body to hold on to too much water and raise the risk of problems like infections.

Doctors do not recommend artificial nutrition and hydration for people with dementia or those who are close to death.

Once artificial nutrition and hydration are started, it may be very difficult for families 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?Will it hurt if we stop the tube feeding?
- Will it hurt if we stop the tube feeding?

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. Other medications can be used to treat discomfort associated with infection. Ask your doctor about the risks and benefits.

(continued on the next page)

Blood Transfusion

A transfusion is where the patient receives blood from a donor which may 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 a treatment that doctors often use for people with cancer. Radiation can help control the cancer or problems caused by the cancer, like pain in the bones. Sometimes radiation causes side effects right away, and other times it takes weeks or months for them to show up. Common side effects are swelling and soreness where the radiation is given. Radiation treatment usually means the person must go to the hospital or clinic many times. If someone is very sick with a serious illness, it's important to think carefully about whether radiation is the right choice.

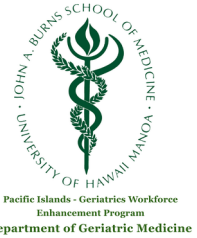
Surgery

Before you think about having surgery, you should know why the surgery is needed, as well as what could go wrong and how surgery might help you. Doctors suggest surgery for different reasons. Sometimes, surgery is done to control a disease, fix or take out something in the body, or to help you feel less pain and be more comfortable. This last type is called palliative surgery.

RESOURCES YOU CAN USE:

Palliative Care is sometimes referred to as Supportive or Concurrent Care and provides strong support for individuals and their loved ones who have 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 on helping people manage the symptoms and stresses of serious illness.

Many thanks to members and supporters of Kōkua Mau, who keep our unique coalition strong. This booklet was updated with their feedback and financial support. Printing was supported by the Health Resources and Services Administration (HRSA) under the Geriatric Workforce Enhancement Program (U1QHP28729), University of Hawai'i.



Palliative Care is available in a variety of settings: in-patient, out-patient and community based. Palliative care in your home or where you live is available throughout Hawai'i and is known as **community-based palliative care**. In the ever-changing landscape of healthcare, please visit our website for the most up-to-date information. For a listing of agencies providing community-based palliative care please visit "**Where to find Palliative Care in Hawai'i**" on our website.

Since 2025, Hawai'i is the first state to comprehensively cover palliative care services for its Med-QUEST (Medicaid) beneficiaries, by adding community palliative care as a preventive service in its Medicaid state plan. We recommend you call your health care provider directly and inquire about palliative care options available to you.

Hospital-based (Inpatient) Palliative Care Programs

Castle Medical Center	808-263-5253
Kaiser Permanente	808-432-7100
Kapi'olani Medical Center for Women & Children	808-983-6000
Maui Memorial Medical Ctr, Palliative Care Coordinator	808-442-5801
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	808-245-1100

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 Maui-Lana'i	808-244-5555
Moloka'i:	Hospice Maui-Moloka'i	808-244-5555
O'ahu:	Bristol Hospice	808-536-8012
	Navian	808-924-9255
	Islands Hospice	808-550-2552
	Malama Ola Health Services	808-543-1188
	St. Francis Hospice	808-547-6500
	VA Hospice	808-433-0256

In the ever-changing landscape of healthcare, please visit our Kōkua Mau website kokuamau.org for the most up-to-date information.