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ACL
Administration for Community Living

Catholic Charities Hawai'i
Circle of Care for Dementia

Supported in part by grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.

Let's Talk Story!!

Advance Care Planning and Dementia

Kōkua Mau

Hope Young
Advance Care Planning Coordinator

Who is *Kōkua Mau*?

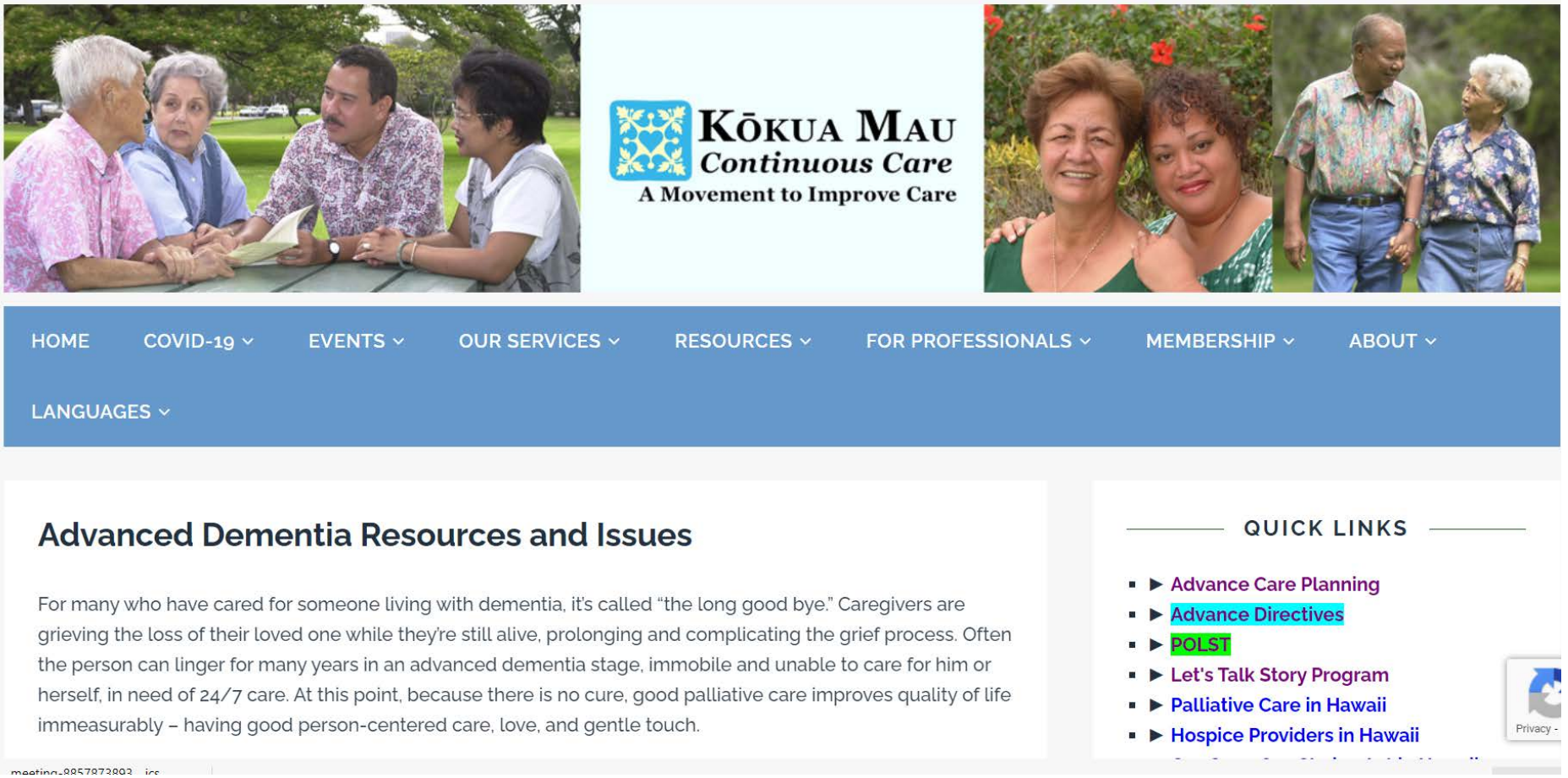
- 501(c)3, community benefit org., statewide (not a state agency)
- Membership –health plans—including HMSA, hospitals, long term care, Senior living communities, churches, temples, hospices, home health agencies, and individuals
- Passionate volunteers across the state

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

Kokua Mau Resources:

- https://kokuamau.org/kokua-mau-resources/advanced-dementia-resources-and-issues/



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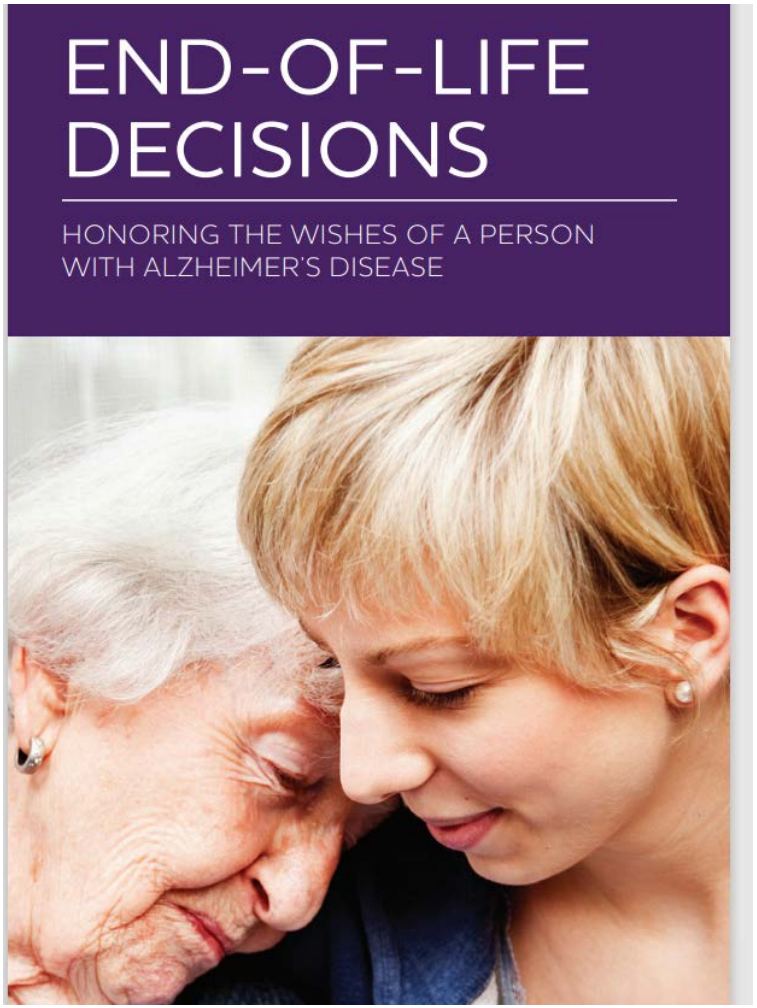
A Movement to Improve Care

Alzheimer's Association Resource

https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf



Alzheimer's Art

https://art-sheep.com/people-with-alzheimers-see-younger-reflections-of-themselves-in-the-mirror/

Articles on ACP specific to dementia considerations :

- https://acpdecisions.org/advance-care-planning-for-patients-with-alzheimers-disease/

- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6393818/

**"Communicating with dead people is easy.
Communicating with live people is hard!"**

KŌKUA MAU
"Continuous Care"

A Movement for Change

Kōkua Mau is leading a *movement* that aims to make advance care planning and open communication about care and support for those with serious illness and their loved ones, including end-of-life care

the cultural norm

"I'm not afraid of death; I just don't want to be there when it happens."

~Woody Allen

the conversation project

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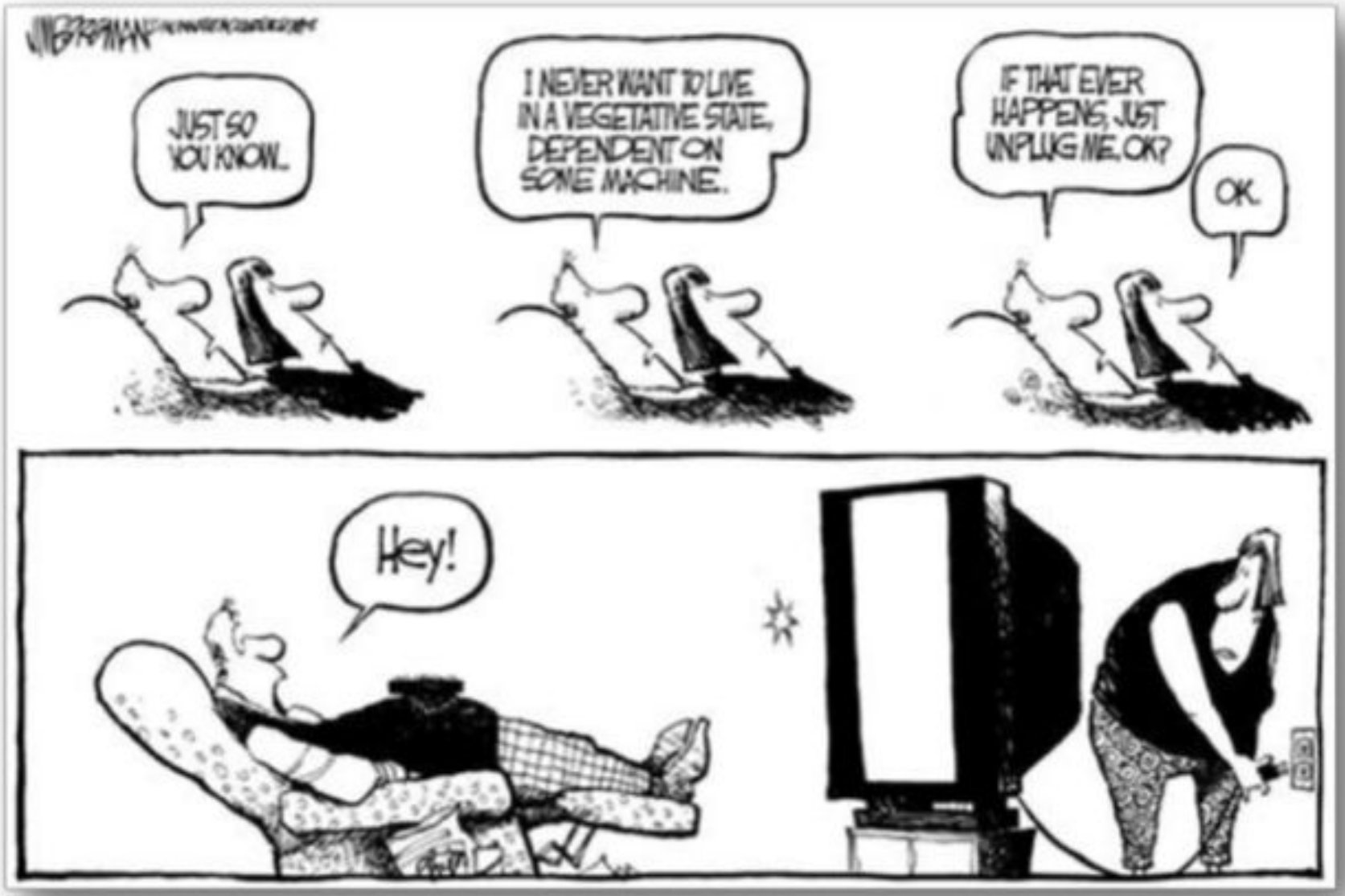

JUST SO YOU KNOW.
I NEVER WANT TO LIVE IN A VEGETATIVE STATE, DEPENDENT ON SOME MACHINE.
IF THAT EVER HAPPENS, JUST UNPLUG ME. OK?
OK.
Hey!

Goals

- Importance of Advance Care Planning
- Having “The Conversation”
- Completing Advance Directives
- Learn tools and tactics for having “the Conversation”

What is Advance Care Planning?

On going process of

Thinking about

Talking about

Writing down

And Sharing

your health care wishes

And who will honor those wishes

Advance Care Planning
Why is it important?

- **COVID 19 has changed the way care is provided in hospitals and doctor's offices**
- No one knows when they may become "Very ill"
- Helps companions to find their voice
- Helps prepare the member and their family for what's coming
- Ease the burden for others having to make tough choices
- Helps assure their wishes are followed

Without Advance Planning

- Crisis-driven care, reactive and unplanned for
- We risk medical error by providing unwanted care
- Family and health care team have to translate what they THINK is wanted rather than is WANTED

Why Should We Plan Ahead?

- In a retrospective study, those with an advance directive were less likely to:
  - Die in hospital
  - Receive a feeding tube
  - Use a ventilator in last month of life

Teno et al, 2007, JAGS

Why Should We Plan Ahead?

- In controlled trials, Advance Care Planning has been shown to:
  - Reduce hospitalization and cost
  - Improve patient and family satisfaction
  - Reduce survivor stress, depression, anxiety
  - Have no impact on mortality

Molloy et al, 2000, JAMA

Detering et al, 2010, BMJ


HURRICANE PREPAREDNESS
* Be Prepared
* Stay Informed
* Take Action
* Maintain Contact

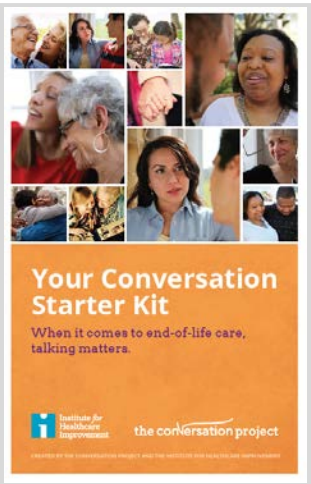
A public engagement campaign dedicated to assure that everyone's wishes for end-of-life care are **expressed and respected.**

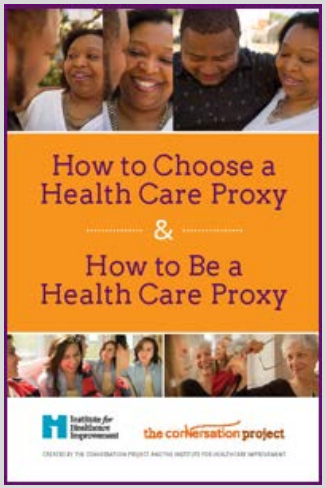
the conversation project

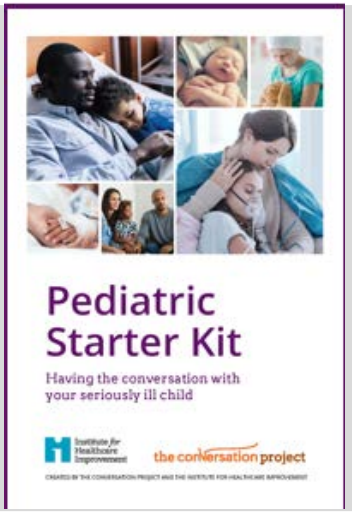
https://kokuamau.org/the-conversation-project/

Accessible: TCP Tools

- Conversation Starter Kit (translations + EMR summary)
- How to Talk to Your Doctor Starter Kit
- Starter Kit for Parents of Seriously Ill Children
- Dementia/Alzheimer's Disease Starter Kit
- How to choose/be a health care agent







the conversation project

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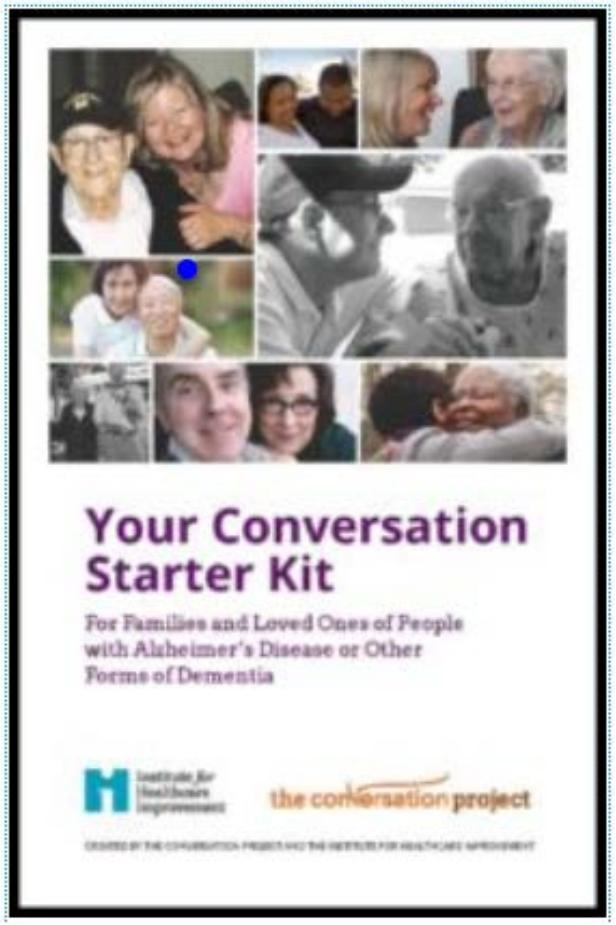
Additional Tools Available:

https://theconversationproject.org/starter-kits/



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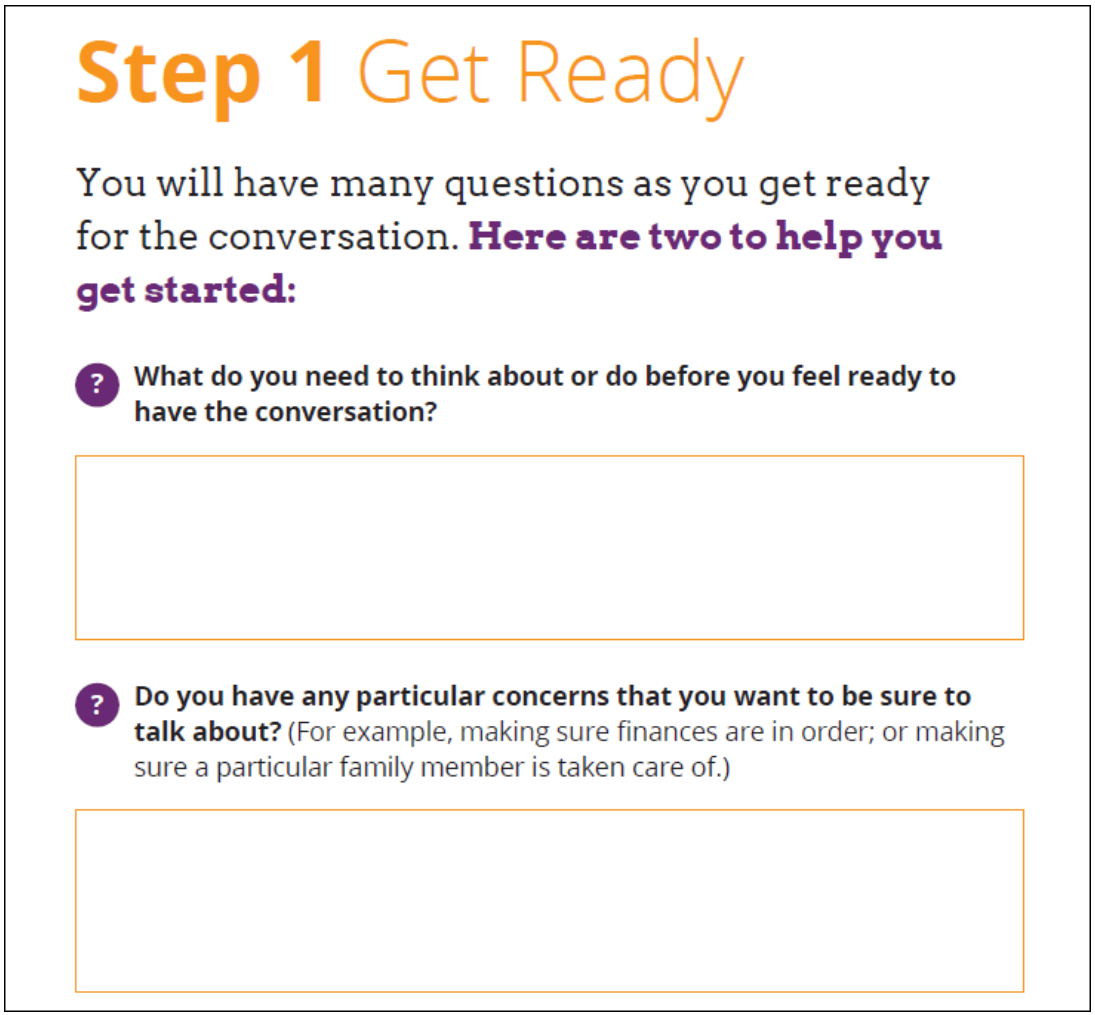
The Starter Kit



Step 1 Get Ready

You will have many questions as you get ready for the conversation. **Here are two to help you get started:**

? **What do you need to think about or do before you feel ready to have the conversation?**

? **Do you have any particular concerns that you want to be sure to talk about?** (For example, making sure finances are in order; or making sure a particular family member is taken care of.)

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The Starter Kit

Step 2 Get Set

What's most important to you as you think about how you want to live at the end of your life? What do you value most? **Thinking about this will help you get ready to have the conversation.**

? **Now finish this sentence: What matters to me at the end of life is...**
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

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What Matters to Me…

- *"I want to say goodbye to everyone I love, have one last look at the ocean, listen to some 90's music, and go."*
- *"A tingling sensation of sadness combined with gratitude and overflowing love for what I leave behind."*
- *"Paced (and with enough space and comfort so that I can make it a 'quality chapter' in my life.) I want time and help to finish things."*
- *"Having my sheets untucked around my feet!"*
- *"Peaceful, pain-free, with nothing left unsaid."*
- *"In the hospital, with excellent nursing care."*

The Starter Kit: Get Set

Where I Stand Scales

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario.

As a patient, I'd like to know...

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
Only the basics about my condition and my treatment				All the details about my condition and my treatment

As doctors treat me, I would like...

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
My doctors to do what they think is best				To have a say in every decision

If I had a terminal illness, I would prefer to...

◯ 1	◯ 2	◯ 3	◯ 4	◯ 5
Not know how quickly it is progressing				Know my doctor's best estimation for how long I have to live

3

The Starter Kit: Step 3 Go

MARK ALL THAT APPLY:

? WHO do you want to talk to?

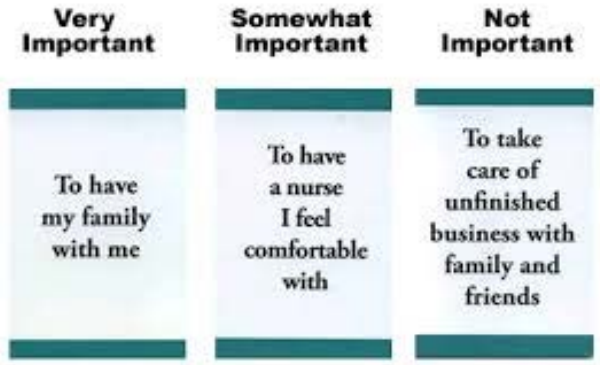
- ☐ Mom
- ☐ Dad
- ☐ Child/Children
- ☐ Partner/Spouse
- ☐ Sister/Brother
- ☐ Faith leader (Minister, Priest, Rabbi, Imam, etc.)
- ☐ Friend
- ☐ Doctor
- ☐ Caregiver
- ☐ Other: _____

? WHEN would be a good time to talk?

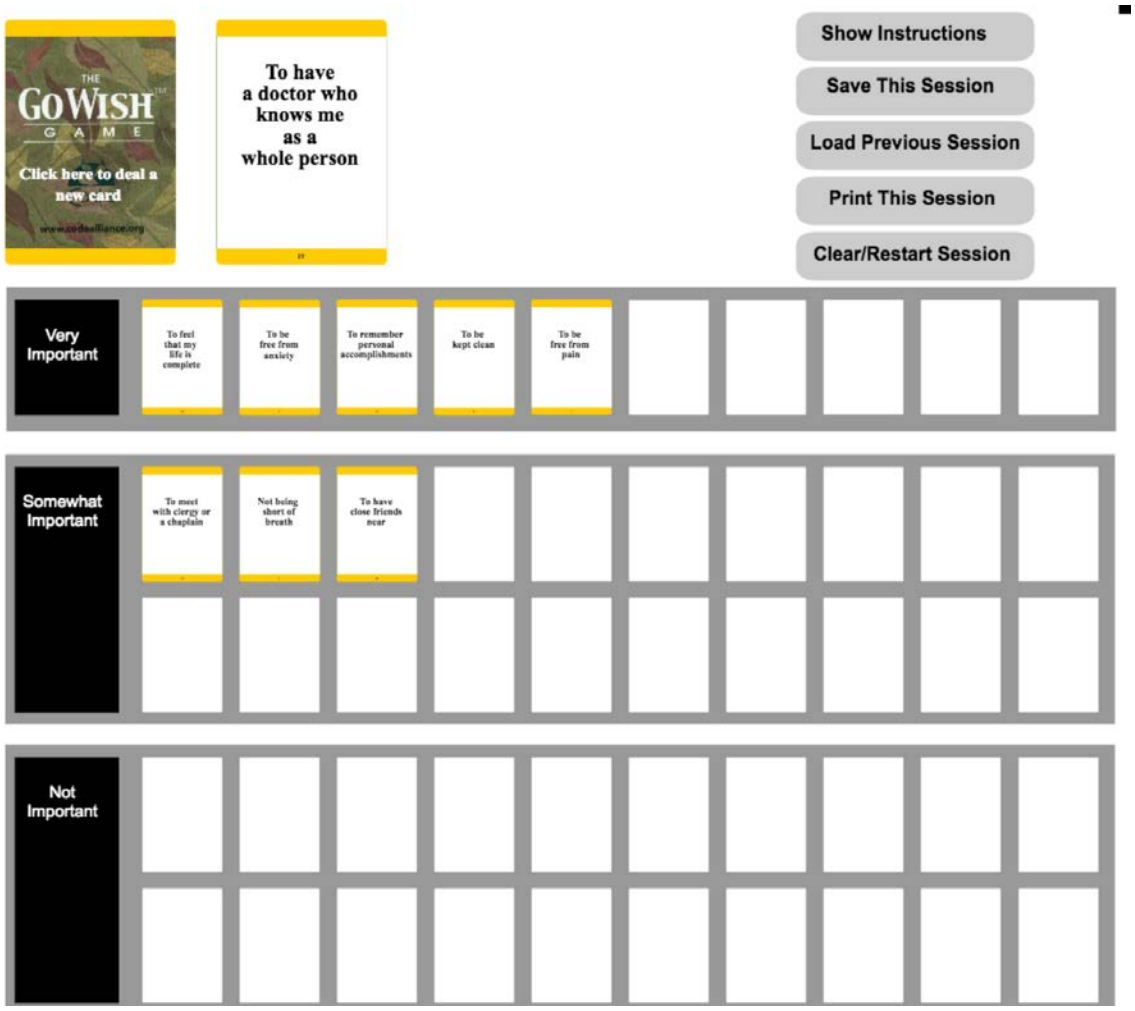
- ☐ The next holiday
- ☐ Before my child goes to college
- ☐ Before my next trip
- ☐ Before I get sick again
- ☐ Before the baby arrives
- ☐ The next time I visit my parents/ adult children
- ☐ At the next family gathering
- ☐ Other: _____

Go Wish Cards

www.GoWish.org



Go Wish Digital Version
www.gowish.org



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Initiating “The Conversation”

- Remind loved ones, “**Everyone over the age of 18** should have an Advance Directive which appoints a Health Care Agent”
- There are no right or wrong answers
- Completing the document and having the conversation with loved ones allows loved ones to support the person’s wishes for care
- It’s a starting point, nothing is set in stone, it can be changed at any time
- “These conversations help us know how to care for each other”

Initiating “The Conversation” (cont.)

- Sometime it is easier initiate the conversation around things the person might ***not*** want, rather than to ask what they **would** want.

- Consider what was important to the person prior to cognitive impairment

Remember during the Pandemic, care is provided differently in hospital settings.

If the unexpected happened,

Who would speak for you?

Would they know what you would want?

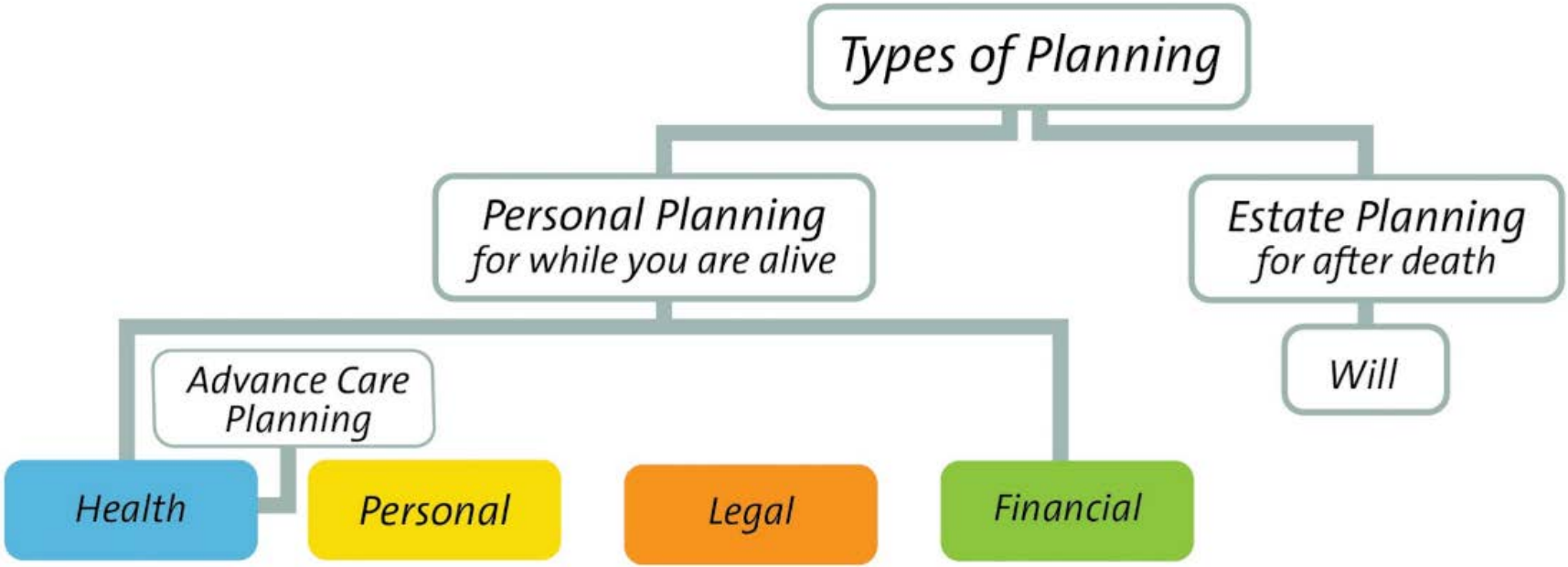
Or possibly what you would not want?

Did you know…

- Everyone over the age of 18 should have an Advance Health Care Directive (AD or AHCD) which appoints a Health Care Agent

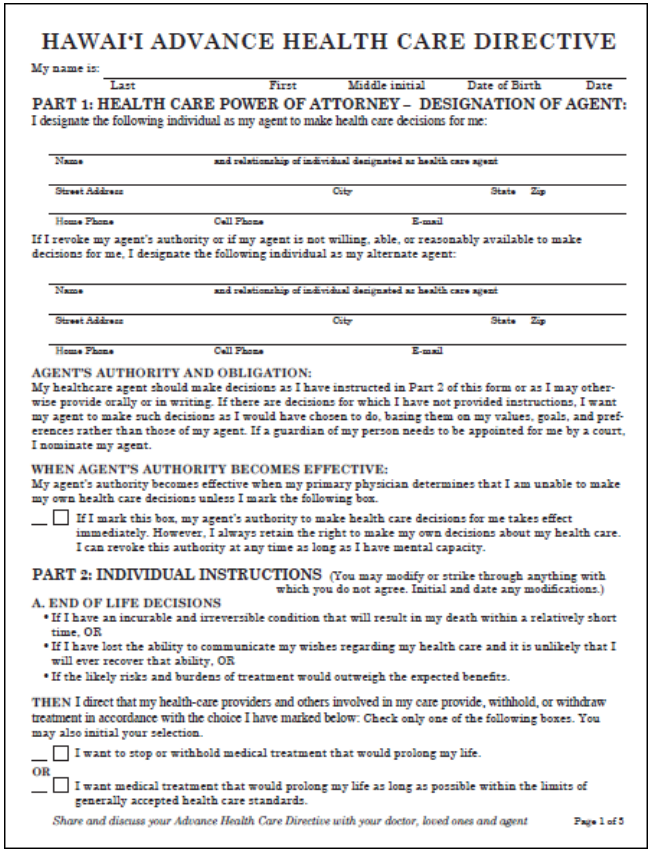
- Without an AD, precious time could be spent trying to designate a Health Care Agent from “interested parties”, there is no next-of-kin hierarchy in the state of Hawaii. If the “interested parties” cannot come to an agreement, it could become a guardianship case, which could take 6 months to resolve

Cover all your bases!



Source: Nidus Personal Planning Resource Centre and Registry

Advance Health Care Directive



HAWAIʻI ADVANCE HEALTH CARE DIRECTIVE

My name is:

Last First Middle initial Date of Birth Date

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 as health care agent

Street Address City State Zip

Home Phone Cell Phone E-mail

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 as health care agent

Street Address City State Zip

Home Phone Cell Phone E-mail

AGENT'S 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 decisions for which I have not 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 guardian of my person needs to be appointed for me by a court, I nominate my agent.

WHEN AGENT'S 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.

__ ☐ If I mark this box, my agent's authority to make health care decisions for me takes effect immediately. However, I always retain the right to make my own decisions about my health care. I can revoke this authority at any time as long as I have mental capacity.

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

A. END OF LIFE DECISIONS

- If I have an incurable and irreversible condition that will result in my death within a relatively short time, OR
- If 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
- If the likely risks and burdens of treatment would outweigh the expected benefits.

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 initial your selection.

__ ☐ I want to stop or 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 5

Available to download on Kokua Mau Website www.kokuamau.org

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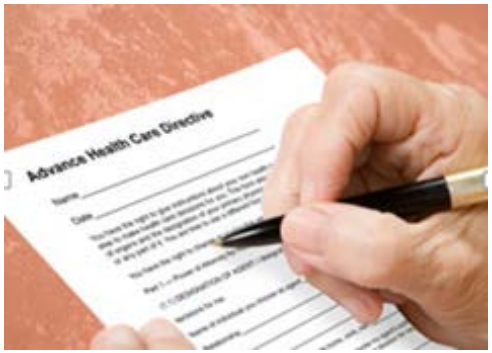
Advance Health Care Directive (AHCD)

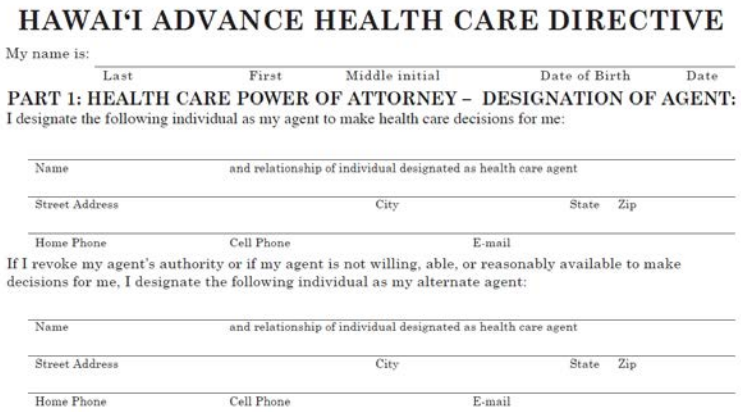
- Legal document completed only when you are of **sound mind**



- Appoints a Health Care Power of Attorney (s)
- State instructions for future choices on your end of life decisions

AHCD – Part 1:
Health Care Power of Attorney (HCPOA)

- Who do you trust to make health care decisions for you when you cannot?
  - Familiar with your personal values
  - Willing and able to make decisions
- Doesn't need to be a family member.
- Select alternate



HAWAIʻI ADVANCE HEALTH CARE DIRECTIVE

My name is: _____

Last First Middle initial Date of Birth Date

PART 1: HEALTH CARE POWER OF ATTORNEY – DESIGNATION OF AGENT:

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Name and relationship of individual designated as health care agent

Street Address City State Zip

Home Phone Cell Phone E-mail

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 as health care agent

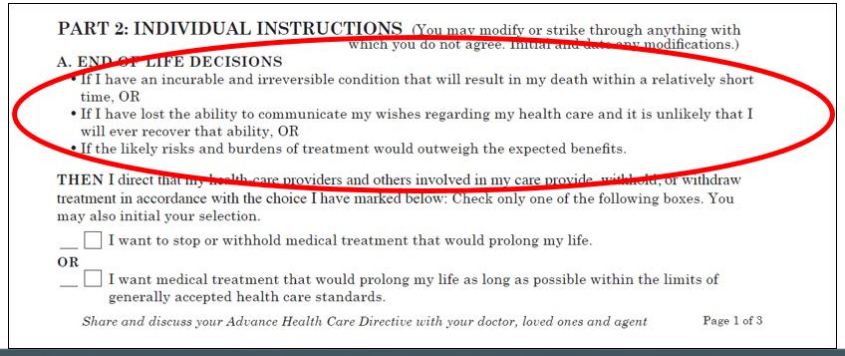
Street Address City State Zip

Home Phone Cell Phone E-mail

AHCD – Part 2
Section A: End of Life Decisions

Becomes effective only when:

- If I have an incurable and irreversible condition that will result in my death within a relatively short time, OR
- If 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
- If the likely risks and burdens of treatment would outweigh the expected benefits



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

A. END-OF-LIFE DECISIONS

- If I have an incurable and irreversible condition that will result in my death within a relatively short time, OR
- If 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
- If the likely risks and burdens of treatment would outweigh the expected benefits.

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 initial your selection.

__ ☐ I want to stop or 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 3

Choice –
Prolong or Not to Prolong Life

- " I want to stop or hold 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"

AHCD – Part 2
Section B: Artificial Nutrition & Hydration

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

B. ARTIFICIAL NUTRITION AND HYDRATION - FOOD AND FLUIDS:

Artificial nutrition and hydration must be provided, withheld or withdrawn in accordance with the choice I have made in the preceding paragraph A unless I mark the following box.

__ ☐ If I mark this box, artificial nutrition and hydration must be provided under all circumstances as long as it is within the limits of generally accepted healthcare standards.

C. RELIEF FROM PAIN:

__ ☐ If I mark this box, I choose treatment to alleviate pain or discomfort even if it might hasten my death.

D. OTHER

__ ☐ If I mark this box, the additional instructions or information I have attached are to be incorporated into my care. (Sign and date each added page and attach to this form.)

Artificial Nutrition and Hydration: Important considerations

- Individual and personal decision.
- In some illnesses (e.g. stroke, esophageal/ throat cancer) artificial nutrition can prolong life.
- In others (Parkinson's, dementia, terminal cancer) artificial nutrition may not prolong life.

- Tube feedings are not recommended for those with dementia. See the official statement at

Section C & D: Relief of Pain and Other Important considerations

- Pain medications to ensure comfort at the end of life can hasten death.
- This is considered ethically acceptable by most medical professionals to provide comfort.
- Again, this is a personal and individual decision.

C. RELIEF FROM PAIN:

__ ☐ If I mark this box, I choose treatment to alleviate pain or discomfort even if it might hasten my death.

D. OTHER

__ ☐ If I mark this box, the additional instructions or information I have attached are to be incorporated into my care. (Sign and date each added page and attach to this form.)

AHCD Part 2 – Section E: What is Important to Me?

- What makes life meaningful?
- What would make quality of life unacceptable?
- If a trial of support is wanted – how long would they want?

E. WHAT IS IMPORTANT TO ME: (Optional. Add additional sheets if needed.) The things that I value and that make life worth living to me are: (examples: gardening, walking my pet, shopping, participating in family gatherings, attending church or temple):

_____

_____

My thoughts about when I would not want my life prolonged by medical treatment (Examples include: If I no longer have the mental capacity to make my own decisions, if I have lost all ability to communicate, if I can no longer safely swallow, etc):

Must be signed in the presence of:

A Notary Public

OR

Two Witnesses

Witnesses

- must be 18 years or older
- Cannot be your health care agent, a health care provider or an employee of a health care facility
- One witness cannot be a relative or have inheritance rights
- Electronic notary possible in COVID pandemic

Next Steps:

- Give copies of your completed Advance Directive to:
  - Your health care agent(s)
  - Your provider and/or preferred health system
  - Keep a copy readily available
  - Share with loved ones
  - Share who you chose to be an agent with loved ones
  - Designate on your driver's license and/or HI state ID that you have an Advanced Health Care Directive
  - Review regularly and update as needed

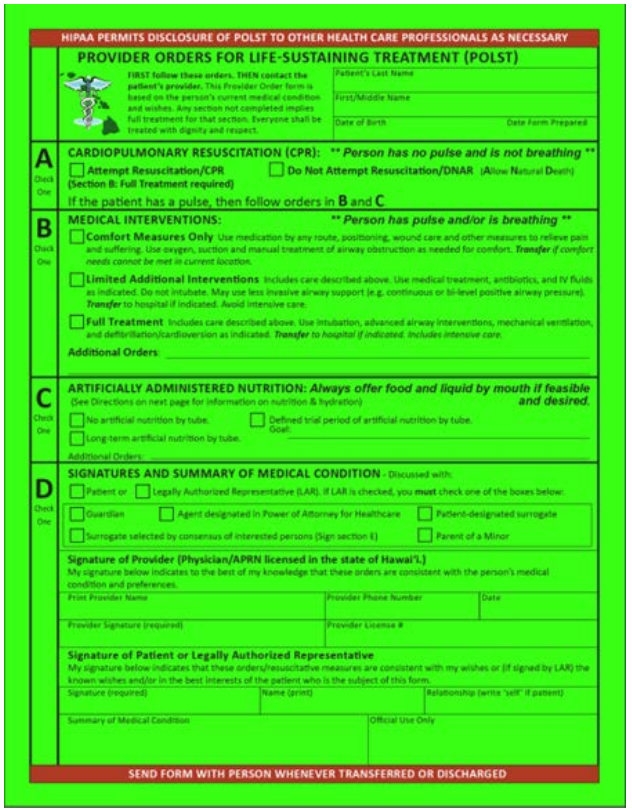
It’s a good day!

Mom has mild cognitive impairment, but it has gotten worse over the years. Today, Mom is having a great day, reminiscing, telling stories, it’s such a joy! I wish she had more of these days.

- Take the opportunity to film Mom with your phone
- Take the opportunity to have “the conversation” and record it for yourself and loved ones

What is POLST?

- **P**rovider
- **O**rders for
- **L**ife
- **S**ustaining
- **T**reatment



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

PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

FIRST follow these orders, THEN contact the patient's provider. This Provider Order form is based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Patient's Last Name

First/Middle Name

Date of Birth

Date Form Prepared

A Check One — CARDIOPULMONARY RESUSCITATION (CPR): ** *Person has no pulse and is not breathing* **

☐ Attempt Resuscitation/CPR (Section B: Full Treatment required)

☐ Do Not Attempt Resuscitation/DNAR (Allow Natural Death)

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

B Check One — MEDICAL INTERVENTIONS: ** *Person has pulse and/or is breathing* **

☐ **Comfort Measures Only** Use medication 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. ***Transfer*** *if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use less invasive airway support (e.g. continuous or bi-level positive airway pressure). ***Transfer*** to hospital if indicated. Avoid intensive care.

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders:

C Check One — ARTIFICIALLY ADMINISTERED NUTRITION: ***Always offer food and liquid by mouth if feasible and desired.***

(See Directions on next page for information on nutrition & hydration)

☐ No artificial nutrition by tube.

☐ Defined trial period of artificial nutrition by tube. Goal:

☐ Long-term artificial nutrition by tube.

Additional Orders:

D Check One — SIGNATURES AND SUMMARY OF MEDICAL CONDITION - Discussed with:

☐ Patient or ☐ Legally Authorized Representative (LAR). If 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 consensus of interested persons (Sign section E) ☐ Parent of a Minor

Signature of Provider (Physician/APRN licensed in the state of Hawai'i.)

My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Provider Name | Provider Phone Number | Date

Provider Signature (required) | Provider License #

Signature of Patient or Legally Authorized Representative

My signature below indicates that these orders/resuscitative measures are consistent with my wishes or (if signed by LAR) the known wishes and/or in the best interests of the patient who is the subject of this form.

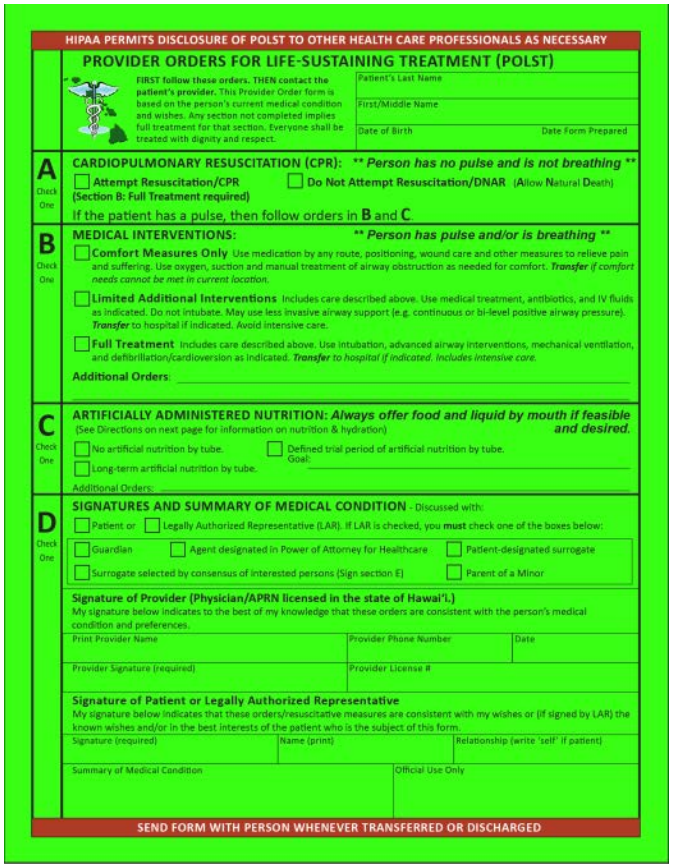
Signature (required) | Name (print) | Relationship (write "self" if patient)

Summary of Medical Condition | Official Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

POLST in Hawaii

Effective 2009, Updated 2014



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

PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

FIRST follow these orders. THEN contact the patient's provider. This Provider Order form is based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Patient's Last Name | First/Middle Name | Date of Birth | Date Form Prepared

A Check One — **CARDIOPULMONARY RESUSCITATION (CPR):** ** *Person has no pulse and is not breathing* **

☐ Attempt Resuscitation/CPR (Section B: Full Treatment required) ☐ Do Not Attempt Resuscitation/DNAR (Allow Natural Death)

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

B Check One — **MEDICAL INTERVENTIONS:** ** *Person has pulse and/or is breathing* **

☐ **Comfort Measures Only** Use medication 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. ***Transfer** if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use less invasive airway support (e.g. continuous or bi-level positive airway pressure). ***Transfer*** to hospital if indicated. Avoid intensive care.

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer** to hospital if indicated. Includes intensive care.*

Additional Orders:

C Check One — **ARTIFICIALLY ADMINISTERED NUTRITION:** ***Always offer food and liquid by mouth if feasible and desired.***

(See Directions on next page for information on nutrition & hydration)

☐ No artificial nutrition by tube. ☐ Defined trial period of artificial nutrition by tube. Goal: ☐ Long-term artificial nutrition by tube.

Additional Orders:

D Check One — **SIGNATURES AND SUMMARY OF MEDICAL CONDITION** - Discussed with:

☐ Patient or ☐ Legally Authorized Representative (LAR). If 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 consensus of interested persons (Sign section E) ☐ Parent of a Minor

Signature of Provider (Physician/APRN licensed in the state of Hawai'i.)

My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Provider Name | Provider Phone Number | Date

Provider Signature (required) | Provider License #

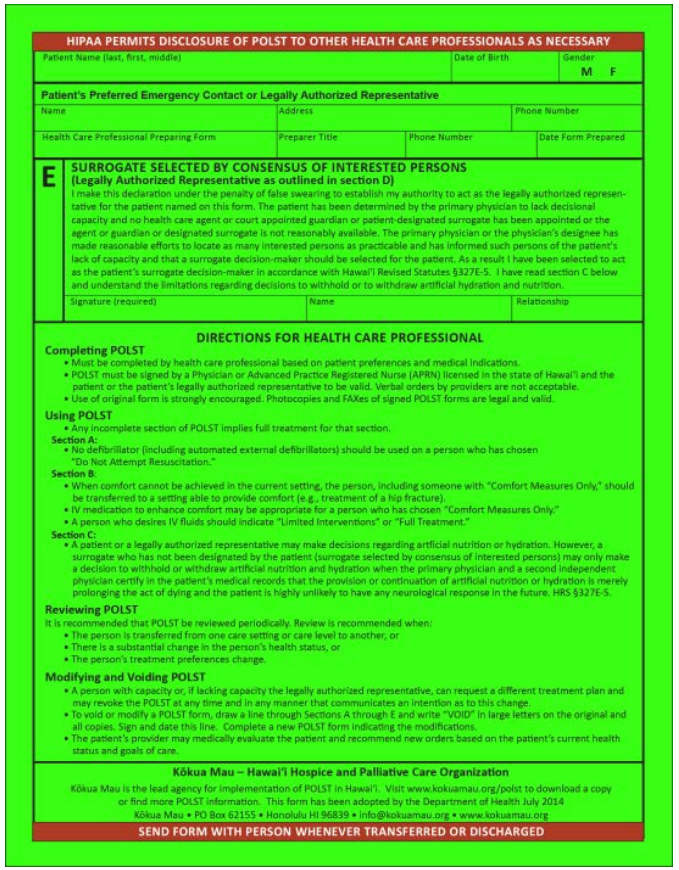
Signature of Patient or Legally Authorized Representative

My signature below indicates that these orders/resuscitative measures are consistent with my wishes or (if signed by LAR) the known wishes and/or in the best interests of the patient who is the subject of this form.

Signature (required) | Name (print) | Relationship (write 'self' if patient)

Summary of Medical Condition | Official Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED



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

Patient Name (last, first, middle) | Date of Birth | Gender M F

Patient's Preferred Emergency Contact or Legally Authorized Representative

Name | Address | Phone Number

Health Care Professional Preparing Form | Preparer Title | Phone Number | Date Form Prepared

E **SURROGATE SELECTED BY CONSENSUS OF INTERESTED PERSONS**
(Legally Authorized Representative as outlined in section D)

I make this declaration under the penalty of false swearing to establish my authority to act as the legally authorized representative for the patient named on this form. The patient has been determined by the primary physician to lack decisional capacity and no health care agent or court appointed guardian or patient-designated surrogate has been appointed or the agent or guardian or designated surrogate is not reasonably available. The primary physician or the physician's designee has made reasonable efforts to locate as many interested persons as practicable and has informed such persons of the patient's lack of capacity and that a surrogate decision-maker should be selected for the patient. As a result I have been selected to act as the patient's surrogate decision-maker in accordance with Hawai'i Revised Statutes §327E-5. I have read section C below and understand the limitations regarding decisions to withhold or to withdraw artificial hydration and nutrition.

Signature (required) | Name | Relationship

DIRECTIONS FOR HEALTH CARE PROFESSIONAL

Completing POLST
- Must be completed by health care professional based on patient preferences and medical indications.
- POLST must be signed by a Physician or Advanced Practice Registered Nurse (APRN) licensed in the state of Hawai'i and the patient or the patient's legally authorized representative to be valid. Verbal orders by providers are not acceptable.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

Using POLST
- Any incomplete section of POLST implies full treatment for that section.

Section A:
- No defibrillator (including automated external defibrillators) should be used on a person who has chosen "Do Not Attempt Resuscitation."

Section B:
- When comfort cannot be achieved in the current setting, the person, including someone with "Comfort Measures Only," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only."
- A person who desires IV fluids should indicate "Limited Interventions" or "Full Treatment."

Section C:
- A patient or a legally authorized representative may make decisions regarding artificial nutrition or hydration. However, a surrogate who has not been designated by the patient (surrogate selected by consensus of interested persons) may only make a decision to withhold or withdraw artificial nutrition and hydration when the primary physician and a second independent physician certify in the patient's medical records that the provision or continuation of artificial nutrition or hydration is merely prolonging the act of dying and the patient is highly unlikely to have any neurological response in the future. HRS §327E-5.

Reviewing POLST

It is recommended that POLST be reviewed periodically. Review is recommended when:
- The person is transferred from one care setting or care level to another, or
- There is a substantial change in the person's health status, or
- The person's treatment preferences change.

Modifying and Voiding POLST
- A person with capacity or, if lacking capacity the legally authorized representative, can request a different treatment plan and may revoke the POLST at any time and in any manner that communicates an intention as to this change.
- To void or modify a POLST form, draw a line through Sections A through E and write "VOID" in large letters on the original and all copies. Sign and date this line. Complete a new POLST form indicating the modifications.
- The patient's provider may medically evaluate the patient and recommend new orders based on the patient's current health status and goals of care.

Kōkua Mau – Hawai'i Hospice and Palliative Care Organization

Kōkua Mau is the lead agency for implementation of POLST in Hawai'i. Visit www.kokuamau.org/polst to download a copy or find more POLST information. This form has been adopted by the Department of Health July 2014

Kōkua Mau • PO Box 62155 • Honolulu HI 96839 • info@kokuamau.org • www.kokuamau.org

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Kōkua Mau
"Continuous Care"
A Movement to Improve Care

HI POLST Form – Information

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

PROVIDER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

FIRST follow these orders. THEN contact the patient's provider. This Provider Order form is based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Patient's Last Name

First/Middle Name

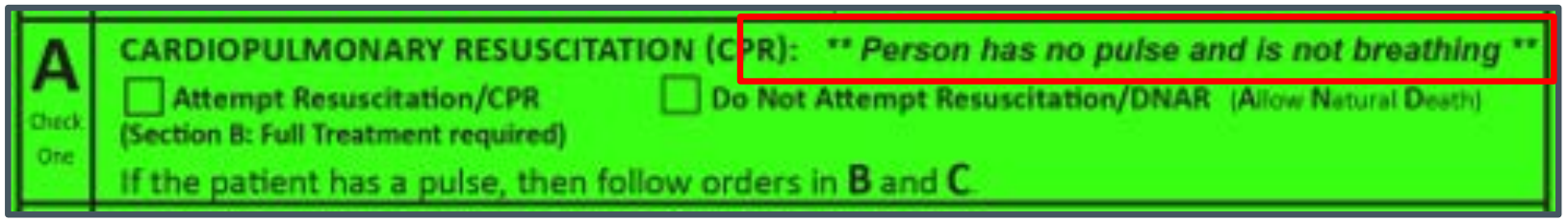
Date of Birth

Date Form Prepared

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

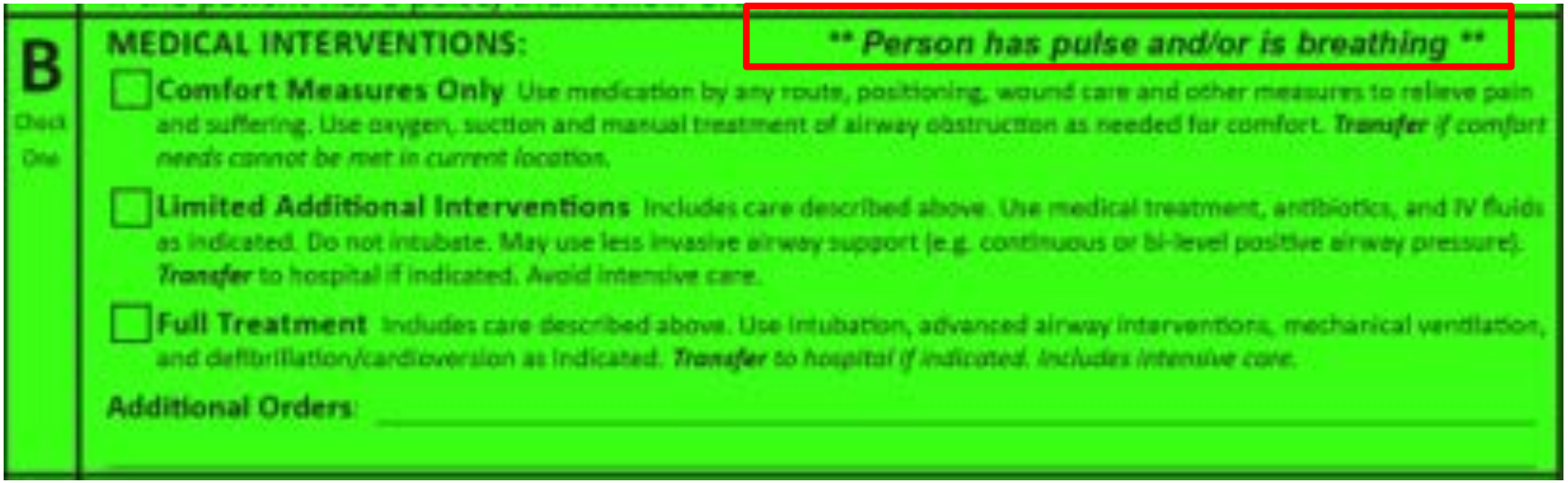
Patient Name (last, first, middle)		Date of Birth	Gender M F
Patient's Preferred Emergency Contact or Legally Authorized Representative			
Name	Address		Phone Number
Health Care Professional Preparing Form	Preparer Title	Phone Number	Date Form Prepared

Section A: Cardiopulmonary Resuscitation (CPR)



Person has no pulse and is not breathing*

Section B:
Medical Interventions



MEDICAL INTERVENTIONS: ** *Person has pulse and/or is breathing* **

B — Check One

☐ **Comfort Measures Only** Use medication 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. ***Transfer*** *if comfort needs cannot be met in current location.*

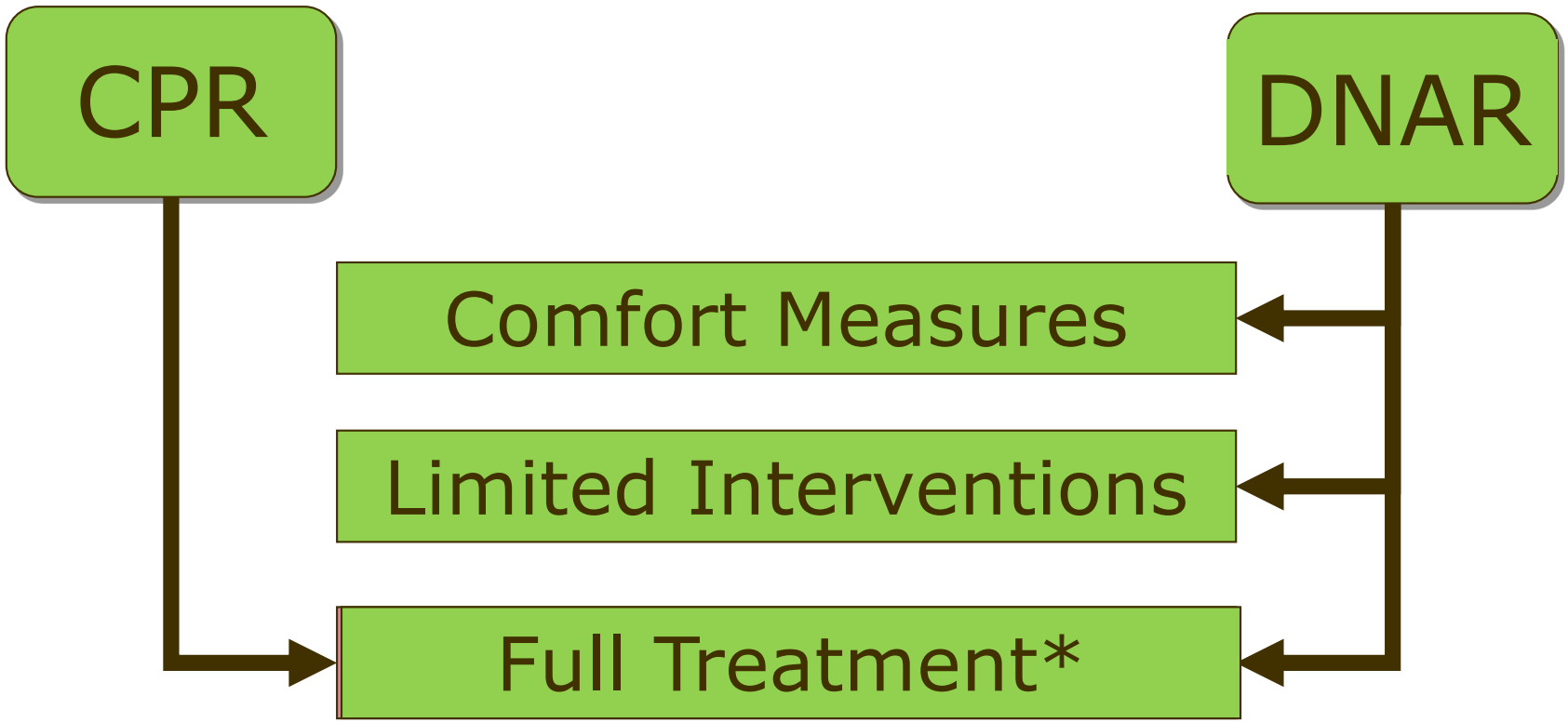
☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use less invasive airway support (e.g. continuous or bi-level positive airway pressure). ***Transfer*** to hospital if indicated. Avoid intensive care.

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders: _____

*****Person has pulse and/or is breathing*****

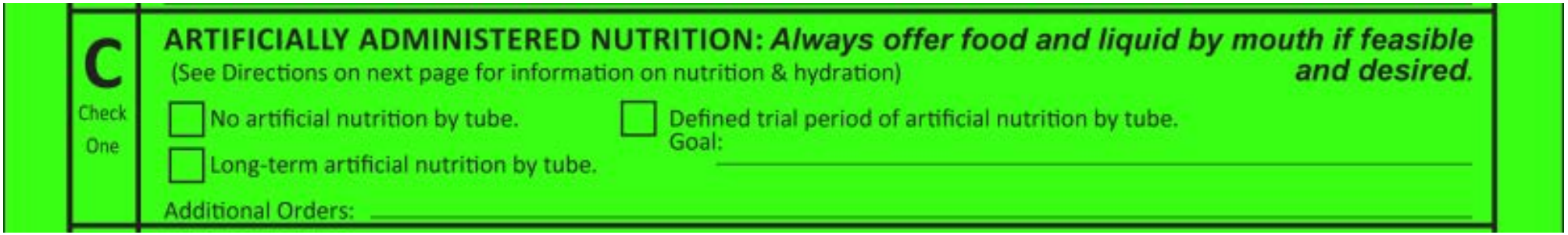
Diagram of POLST Medical Interventions



*Consider time/prognosis factors under "Full Treatment"

"Defined trial period. Do not keep on prolonged life support."

Section C: Artificially Administered Nutrition



C

Check One

ARTIFICIALLY ADMINISTERED NUTRITION: ***Always offer food and liquid by mouth if feasible and desired.***

(See Directions on next page for information on nutrition & hydration)

☐ No artificial nutrition by tube.

☐ Defined trial period of artificial nutrition by tube.
Goal: _____

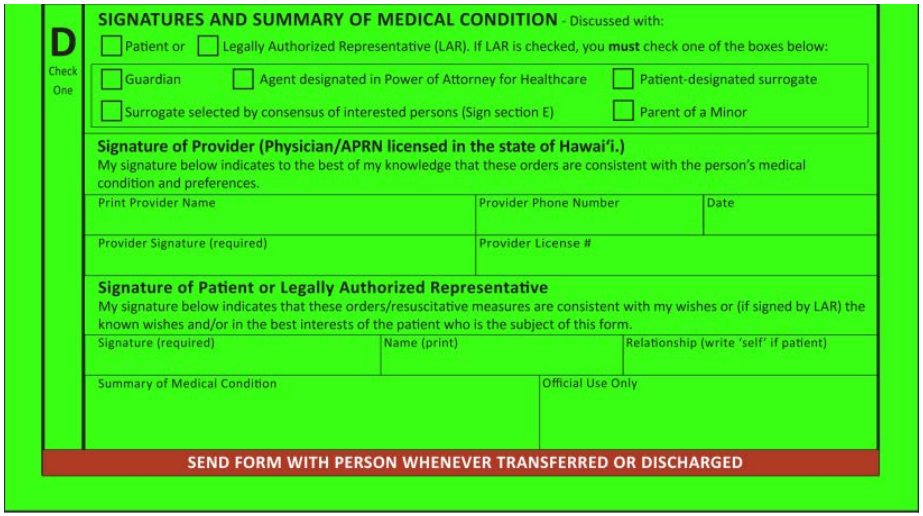
☐ Long-term artificial nutrition by tube.

Additional Orders: _____

Always offer food and liquid by mouth if feasible and desired.

POLST
Section D – Important Signatures!

- Physician or Advance Practice Registered Nurse (APRN) **and**
- Patient **or** their Legally Authorized Representative (LAR)
- LAR - Agent designated for Health care Power of Attorney ;
  - Parent of a Minor
  - Patient-designated Surrogate
  - Surrogate selected by consensus of interested persons
  - Guardian



D Check One

SIGNATURES AND SUMMARY OF MEDICAL CONDITION - Discussed with:

☐ Patient or ☐ Legally Authorized Representative (LAR). If 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 consensus of interested persons (Sign section E) ☐ Parent of a Minor

Signature of Provider (Physician/APRN licensed in the state of Hawai'i.)

My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Provider Name	Provider Phone Number	Date
Provider Signature (required)	Provider License #	

Signature of Patient or Legally Authorized Representative

My signature below indicates that these orders/resuscitative measures are consistent with my wishes or (if signed by LAR) the known wishes and/or in the best interests of the patient who is the subject of this form.

Signature (required)	Name (print)	Relationship (write 'self' if patient)
Summary of Medical Condition	Official Use Only	

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Surrogate: Designated or Non-Designated

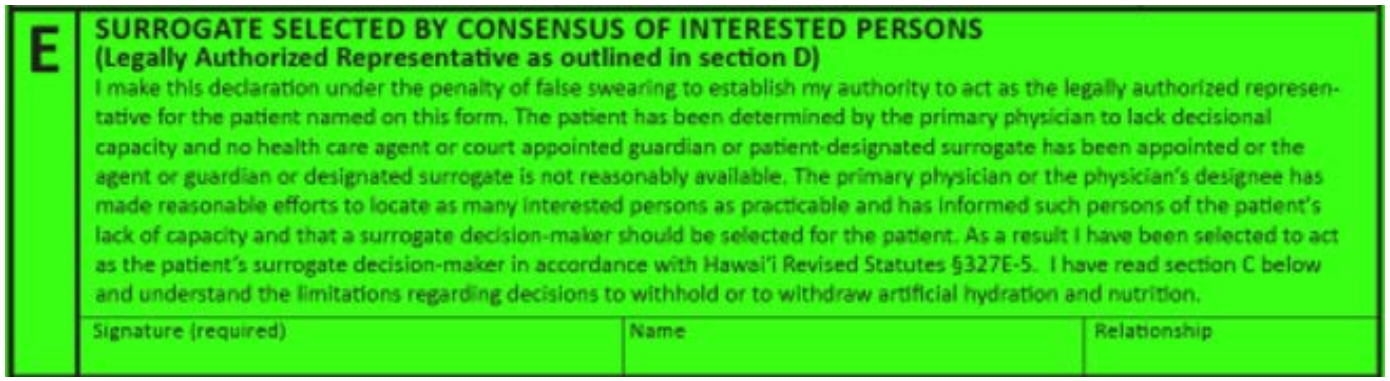
Under the Uniform Health Care Decisions Act (Chapter 327E) there are 2 types of surrogate:

- **Designated Surrogate** – A patient may designate any individual to act as a surrogate by personally informing the supervising health-care provider.

- **Non-Patient Designated Surrogate –** one who is selected through agreement by all interested persons when the patient did not designate anyone and patient lacks decisional capacity.

Section E: Surrogate Information

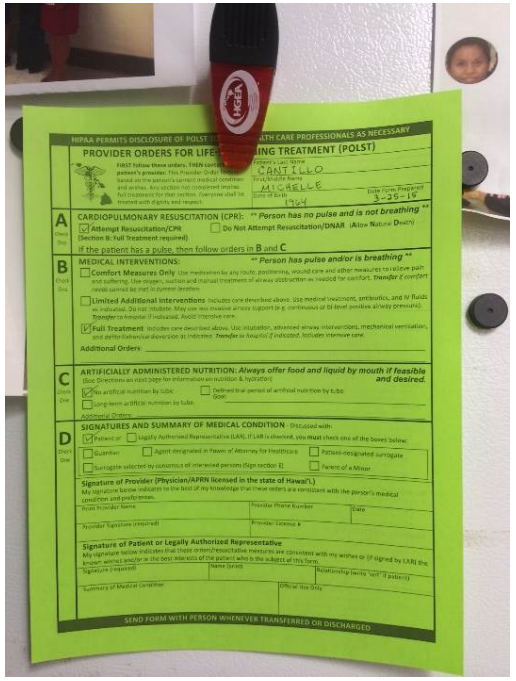
- Section E **only** needs to completed if the patient lacks capacity and has not designated a health care power of attorney
- ***Non-Designated Surrogate:*** This individual is appointed in accordance with HRS 327E, & has limitations placed upon him or her with respect to decisions about withholding or with-drawing artificial hydration & nutrition.



E	SURROGATE SELECTED BY CONSENSUS OF INTERESTED PERSONS (Legally Authorized Representative as outlined in section D) I make this declaration under the penalty of false swearing to establish my authority to act as the legally authorized representative for the patient named on this form. The patient has been determined by the primary physician to lack decisional capacity and no health care agent or court appointed guardian or patient-designated surrogate has been appointed or the agent or guardian or designated surrogate is not reasonably available. The primary physician or the physician's designee has made reasonable efforts to locate as many interested persons as practicable and has informed such persons of the patient's lack of capacity and that a surrogate decision-maker should be selected for the patient. As a result I have been selected to act as the patient's surrogate decision-maker in accordance with Hawai'i Revised Statutes §327E-5. I have read section C below and understand the limitations regarding decisions to withhold or to withdraw artificial hydration and nutrition.		
	Signature (required)	Name	Relationship

Practical considerations

- Recommended to be printed on **lime green** paper (but any color, including black and white is acceptable)
- A copy of the POLST form is legal
- Recommended to be kept in a visible place at home:
  - Refrigerator
  - Bedroom door
  - Bedside table
  - Medicine cabinet
- A copy should be given to EMS personnel
- POLST is not transferable from state to state

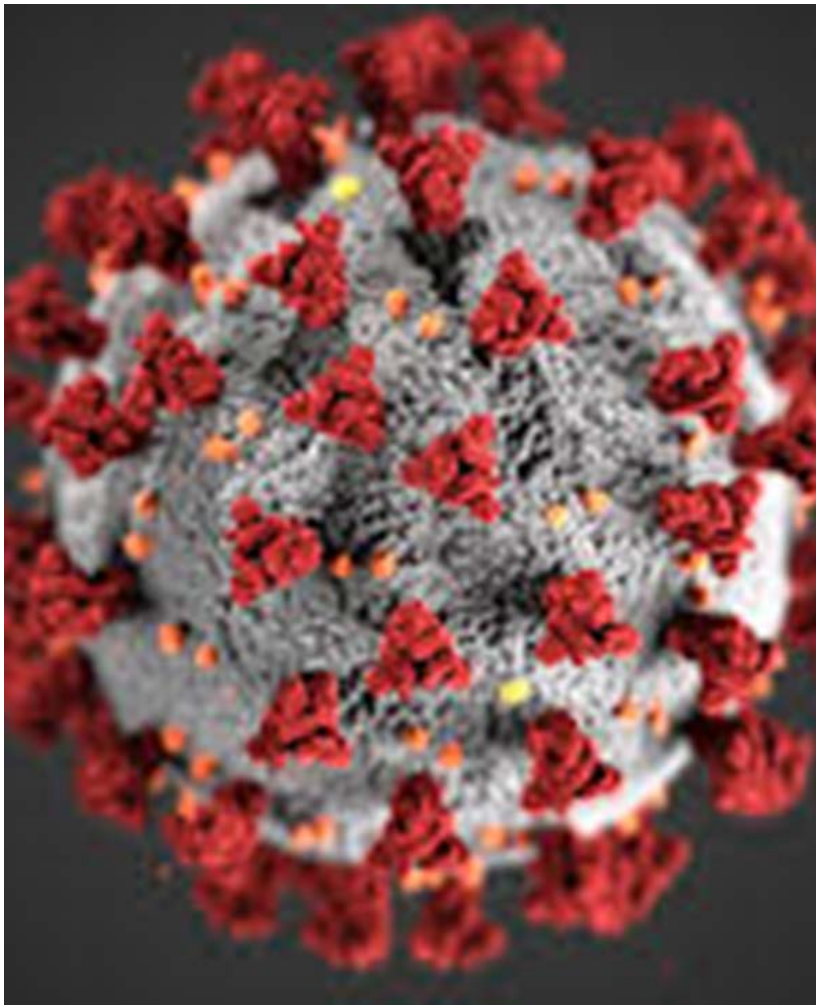


Who Would Benefit from Having a POLST Form?

- Chronic, progressive illness
- Serious health condition
- Medically frail
- A person for whom you would issue an in-patient DNR order
- “Would you be surprised if this patient died within the next year?”
- Those who do not want to be taken to the hospital during the pandemic

Considerations surrounding POLST

- Covid19 has changed the way hospitals provide care; visitors are generally not allowed unless patient is dying
- Goals of care conversations can help determine how to best support the individual



Advance Health care Directive vs. POLST

Advance Directives	POLST
For anyone 18 years or older	Persons at any age with serious illness
Identifies wishes for **future** healthcare	Indicates decisions about **current** treatments
Appoints a health care representative	Legally authorized representative can be noted
Does not translate into orders for EMS personnel	Actionable orders
CPR/DNR not addressed	CPR/DNR order

Remember…

Everyone needs an

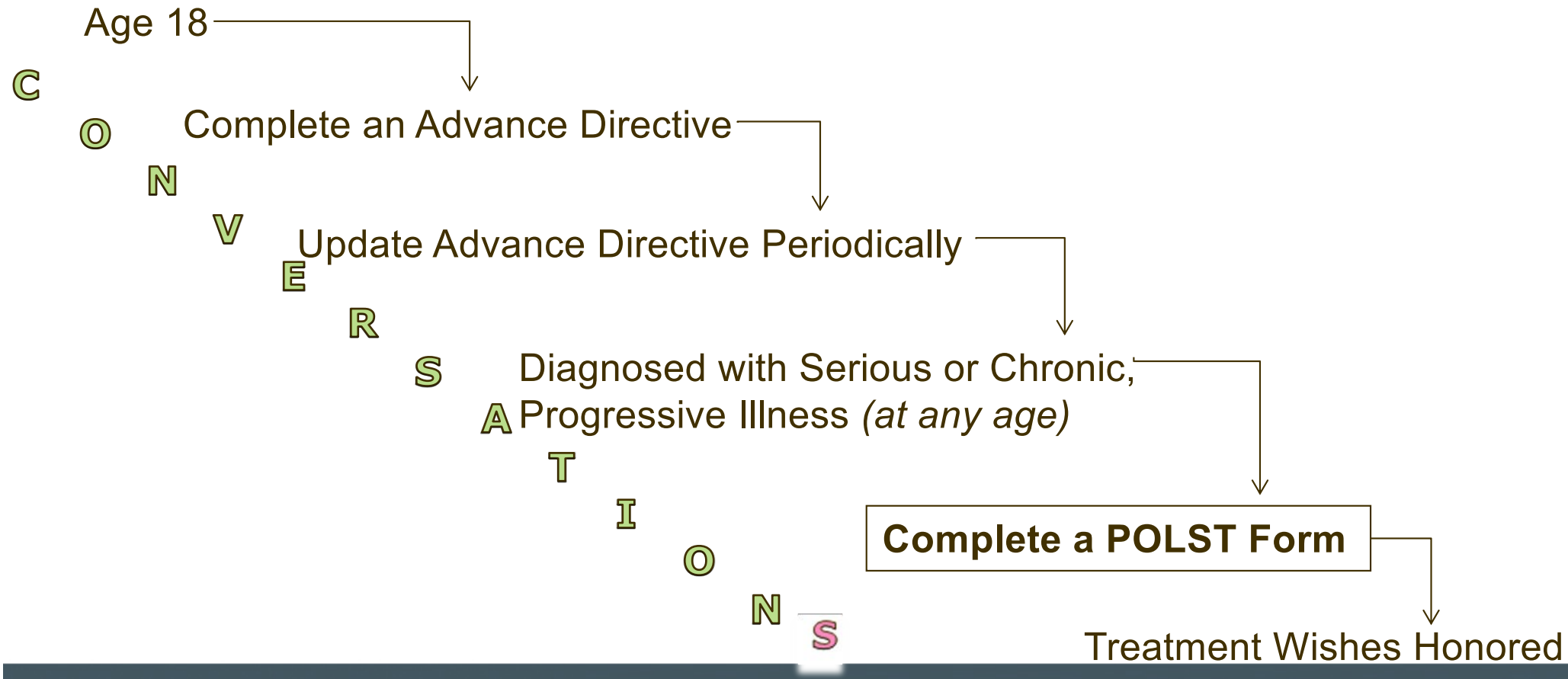
Advance Directive

not everyone needs a

POLST

Where Does POLST Fit In?

Advance Care Planning Continuum



ACP Conversations

- Opportunity to increase awareness of different courses of action possible
- Introduce Palliative Care (HMSA Supportive Care) for individuals with serious illness pursuing curative treatments
- Introduce Hospice for individuals with a terminal diagnosis
- Change the question:

  “What’s the matter with me?”

  to

  “What matters TO me?

What Is Palliative Care?

- "Palliative care is specialized medical care for people living with a serious illness.
  - This type of care is focused on providing relief from the symptoms and stress of a serious illness.
  - The goal is to improve quality of life for both the patient and the family.

- 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)

Palliative Care-Supportive Care benefit

- Includes, but is not limited to pain management
- In Hawaii, services are often provided by Hospice providers, but is not hospice care.
- Individuals using Palliative care can continue with curative treatment.

Hospice Referrals

- Hospice should be introduced as early as possible when diagnosed with a terminal illness to provide an extra layer of support for individuals and their loved ones.

- Hospice is a team-approach; a physician, a nurse, a social worker, an aide, and a spiritual advisor all assigned to the individual.

State Hospice Providers

https://kokuamau.org/hospice-providers/

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

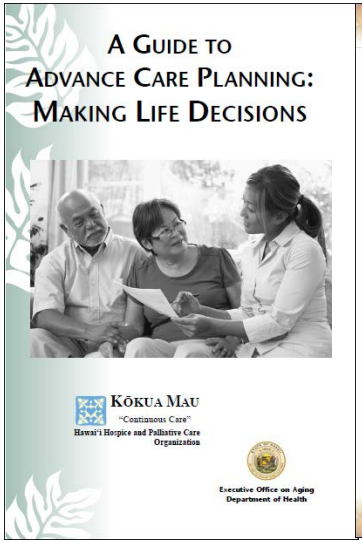
HMSA Case Management Program	1-844-378-9997	808-948-5377
Kaiser Permanente		808-432-8046
Kupu Care by Hawaii Care Choices (Hilo)		808-934-2913
Kōkua Kalihi Valley Home-Based Palliative Care Services		808-791-9410
Palliative Medicine Partners, (Kaua'i)		808-245-7277
St. Francis Supportive Care (O'ahu)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

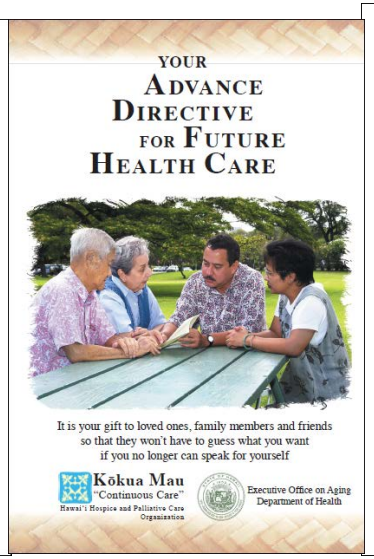
Join Us at Kōkua Mau!!

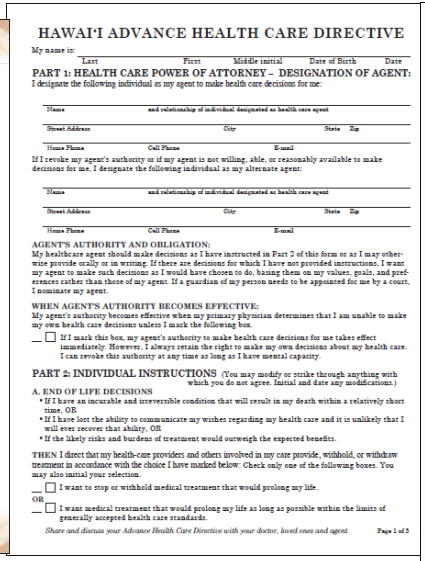
Resources and other activities

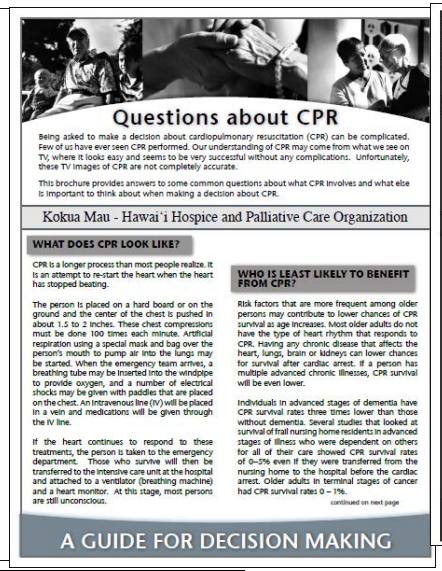
- Join Kōkua Mau Mailing List
- Download materials from the Kōkua Mau Website – look for the Tool Kit
- Use the new translations
- Request a speaker from Kōkua Mau's **Let's Talk Story** Program – We are ready to talk with your church or other group!

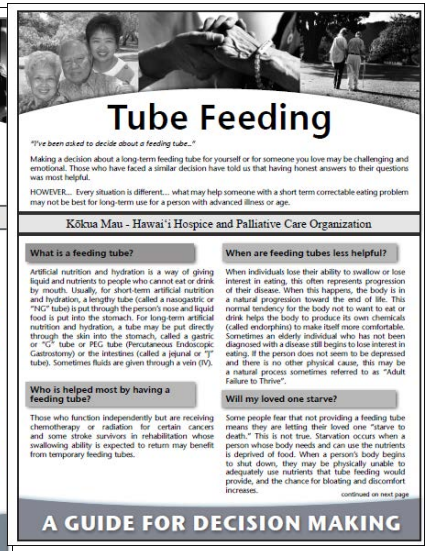
Kokua Mau Resources

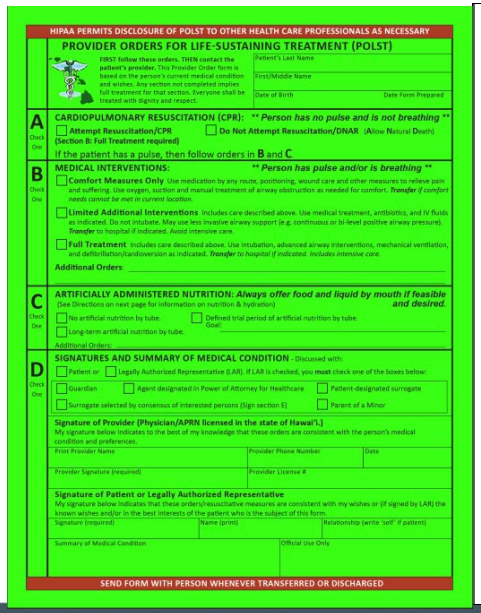


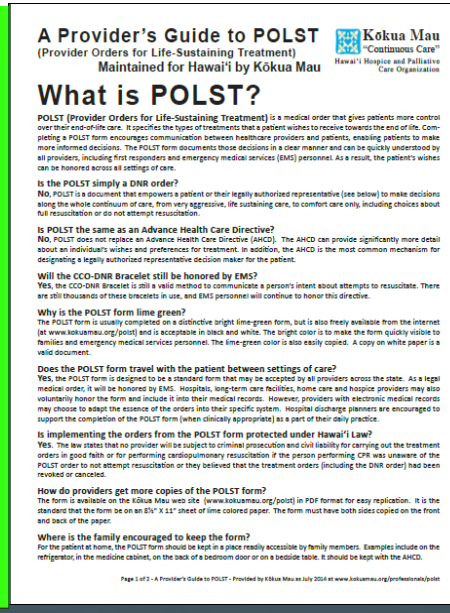


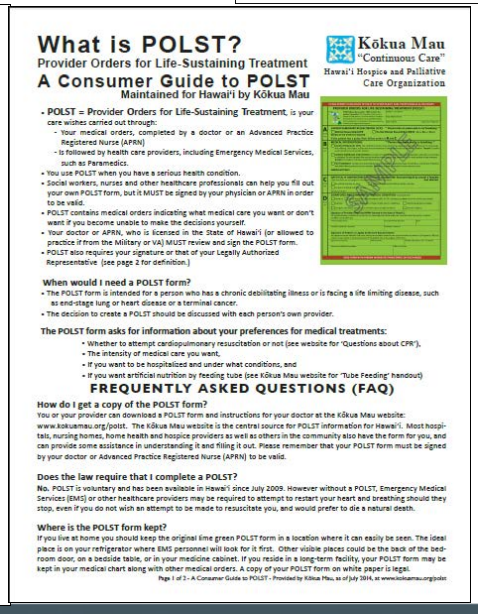












Chinese simplified Hawaii **Advance** Health Care **Directive**
Chinese traditional Hawaii **Advance** Health Care **Directive**
Ilocano Hawaii **Advance** Health Care **Directive**
Japanese Hawaii Advance Health Care Directive
Korean Hawaii **Advance** Health Care **Directive**
Marshallese Hawaii Advance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

Kōkua Mau
"Continuous Care"
A Movement to Improve Care

Kokua Mau Contact

Jeannette Koijane, Executive Director
jkoijane@kokuamau.org
808-585-9977
Hope Young, ACP Coordinator
hope@kokuamau.org
808-221-2970

www.theconversationproject.org


Thank You!

CATHOLIC CHARITIES
HAWAI'I
CIRCLE OF CARE FOR DEMENTIA

Dementia and Dysphagia

Dorothy Arriola Colby
Hale Ku'ike
Director of Community Engagement
Positive Approach to Care Trainer

Dysphagia & Dementia

- Experiencing any issues with swallowing is known as dysphagia.
- The condition can be caused by several factors, including damage to parts of the brain that control swallowing.
- It can be an acute onset (from a stroke, for example) or progressive, as is the case for those living with dementia.
- 9 out of 10 people with dementia will experience dysphagia at some point

Symptoms of Dysphagia

- Drooling saliva, food or fluid
- Effortful or prolonged chewing
- Pocketing of food in cheeks
- Pooling of fluid in mouth
- Spitting out food
- Nasal regurgitation
- Coughing when drinking or eating
- Wet or gurgly voice
- Food getting stuck in the throat or neck region
- Pain or discomfort with swallowing
- Unexplained weight loss
- Chest infections or aspiration pneumonias.

Care Strategies for Dysphagia

- Get a speech pathologist assessment and recommendations on
  - Food and liquid consistencies
  - Positioning
- Create a familiar and forgiving dining environment
- Make food visually appealing
- Watch “Adam’s apple” make sure they have actually swallowed
- Alternate between food and liquid to help clear any residue in mouth
- If you see signs of not swallowing, stop and take a step back and reassess safety of eating.
- Offer food and drink, but do not force.

Final message related to dysphagia and dementia

With dementia, it is about our relationship

NOT about getting it in & getting it done

Learn More About Dysphagia (swallowing difficulties) and Aging

https://geriatrics.jabsom.hawaii.edu/resources/

This video is available in English, Samoan, Ilocano and Chuukese!

Winter 2020 Zoom Workshop Series

Geriatrician Perspectives on Dementia, Caregiving, and Brain Health for Caregivers of Persons Living with Memory Loss

- **Presented by Dr. Kamal Masaki and Dr. Aida Wen**

https://bit.ly/CCH2020DementiaWorkshops

Healthy Brain Aging and Dementia
• Nov 18 • 10:30-noon (*note later start time*)

Non-Medication Strategies for Dementia Behaviors
• Nov 24 • 10:00-11:30 am

Principles of Medication Use in Older People
• Dec 3 • 10:00-11:30 am

The 3 D's: Dementia, Delirium and Depression: Knowing the Difference
• Dec 10 • 10:00-11:30 am

Thank you!

Thank you so much for your desire to learn and your commitment to making a positive difference!

Please also help us support this grant by completing a short anonymous demographic and quality survey after this webinar. Your feedback is important to us, and helps us to keep providing these free educational events to our community.

To learn more about the Hawaii Circle of Care for Dementia visit, www.catholiccharitieshawaii.org/dementia/

To learn more about Kokua Mau visit www.kokuamau.org

Please help us support this grant by completing this short 5-question post-test poll. All answers are anonymous.

Thank you for your participation!

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