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HADI Hawai‘i Alzheimer’s Disease Initiative

A PROJECT OF THE UH CENTER ON AGING

www.hawaii.edu/aging/hadi

Update from Kōkua Mau: Advance Care Planning and Dementia

August 29, 2017

Jeannette Koijane, MPH
Executive Director

KŌKUA MAU
"Continuous Care"
Hawai'i Hospice and Palliative Care Organization

Who is Kōkua Mau?

KŌKUA MAU
"Continuous Care"
Hawai'i Hospice and Palliative Care Organization

- 501(c)3, community benefit org., statewide
- Membership – hospices, health plans, MCOA, hospitals, long term care, spiritual
- Work with seriously ill people & their loved ones to understand the decisions they may need to make
- Provide professional networking & training
- Work on policy & legislation

Main Activities

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- Hired an Advance Care Planning (ACP) Coordinator – Hope Young
- Let's Talk Story
- Research on ACP leading to an Education Campaign
- ACP Survey

Let's Talk Story - Revamped Speakers Bureau

- 19 trained speakers to go where people work, live and pray
- 2 sessions – Get the conversation going; Specifics of POLST and AD
- Use Starter Kit from The Conversation Project
- Talks well received – Useful (100%), 89% committed to having conversations

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Let's Talk Story - Continued

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- In 2016
  - 14 public talks - 400 people, 16 professional talks - 600 people
  - Informational tables at 15 events (2500+ people)
- In 2017 – 29 talks (450 people), 12 professional talks (510 attending);
- Looking for pilot sites for workplace wellness initiatives – Everyone in Healthcare needs to have the conversation and needs their own Advance Directive

Education Campaign

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- Let's make these conversations the norm BEFORE they are needed
- Education campaign is planned but first we need RESEARCH
  - Telephone survey on Attitudes towards ACP
  - Focus Groups

ACP Survey

- Oahu-wide short survey created to determine:

1. What ACP Processes are currently in place?

Goal: What are the gaps if we map the whole process? Design pilots to address the gaps.

2. What ACP data do you collect? Who do you share it with?

Goal: Overview of what is happening in the state? What should we be collecting OR What would meaningful data be?

To improve the system, we need to understand it!!

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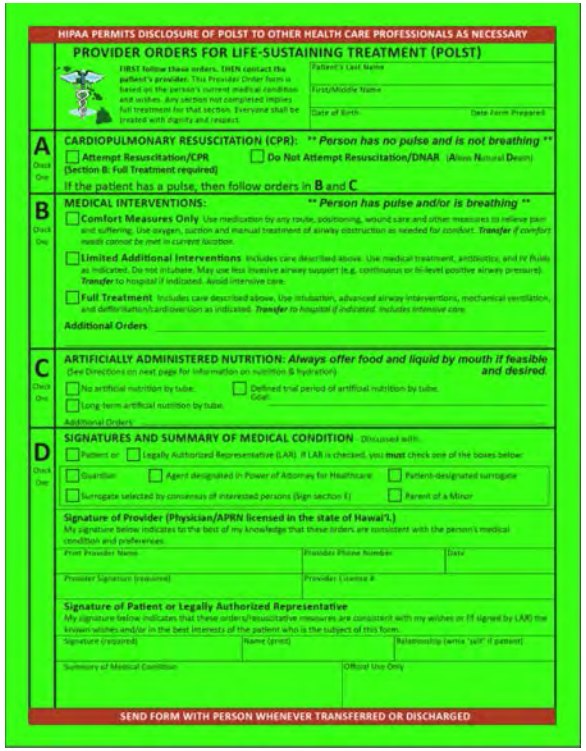
What is POLST?

- Provider
- Orders for
- Life
- Sustaining
- Treatment



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

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

(Section B: Full Treatment required)

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

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

☐ Comfort Measures Only. Use 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 — 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 — 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

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What is POLST?

- Provides direction for healthcare providers during serious illness – Right Now Orders
- Allows for “shades of gray” in choices e.g. CCO-DNR bracelet is only “yes/no” choice
- Portable document that transfers with the patient
- Brightly colored, standardized form for entire state of HI

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Why POLST?

1. Patient wishes often are not known
   - The Advance Healthcare Directive (AHCD) may not be accessible
   - Wishes may not be clearly defined in AHCD
   - DNR wishes not documented
2. Allows healthcare providers to know and honor wishes during serious illness

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Why POLST? (con't)

3. Gives clear, concise information for Emergency Medical Personnel (EMS) that they can act on
4. Helps family/loved ones/agents process patients known wishes or values from the AHCD to a real time actionable plan
5. Portable across all settings in Hawaii

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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?”

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POLST in Hawaii

- One form for entire state.
- Use not mandated.
- **Honoring form is mandated**.
- Provides immunity from civil or criminal liability.

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POLST in Hawaii

- Kokua Mau is lead agency
- Grassroots efforts of local providers throughout the state
- Form and resources available at **www.kokuamau.org**
- Legal changes in 2014
  - "Provider's" Orders:

    Expanded to allow APRN to sign the order

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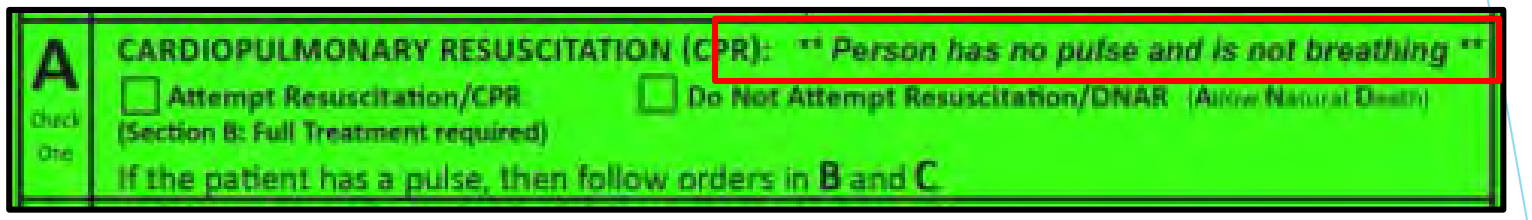
Section A: Cardiopulmonary Resuscitation (CPR)



Person has no pulse and is not breathing*

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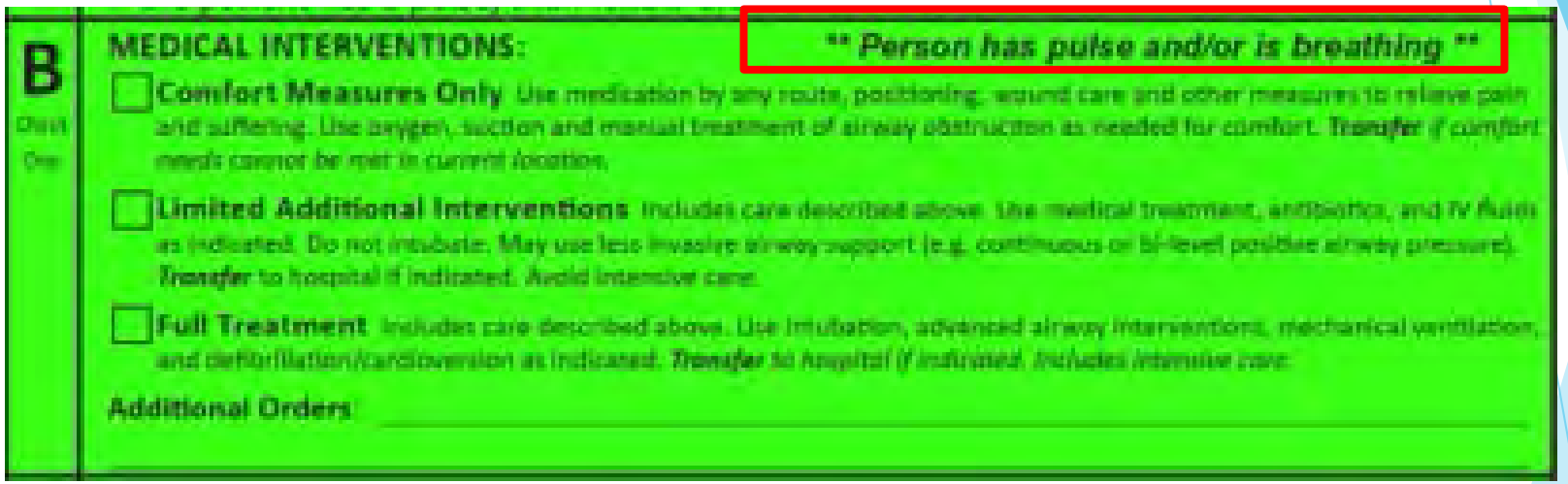
Section B: Medical Interventions



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

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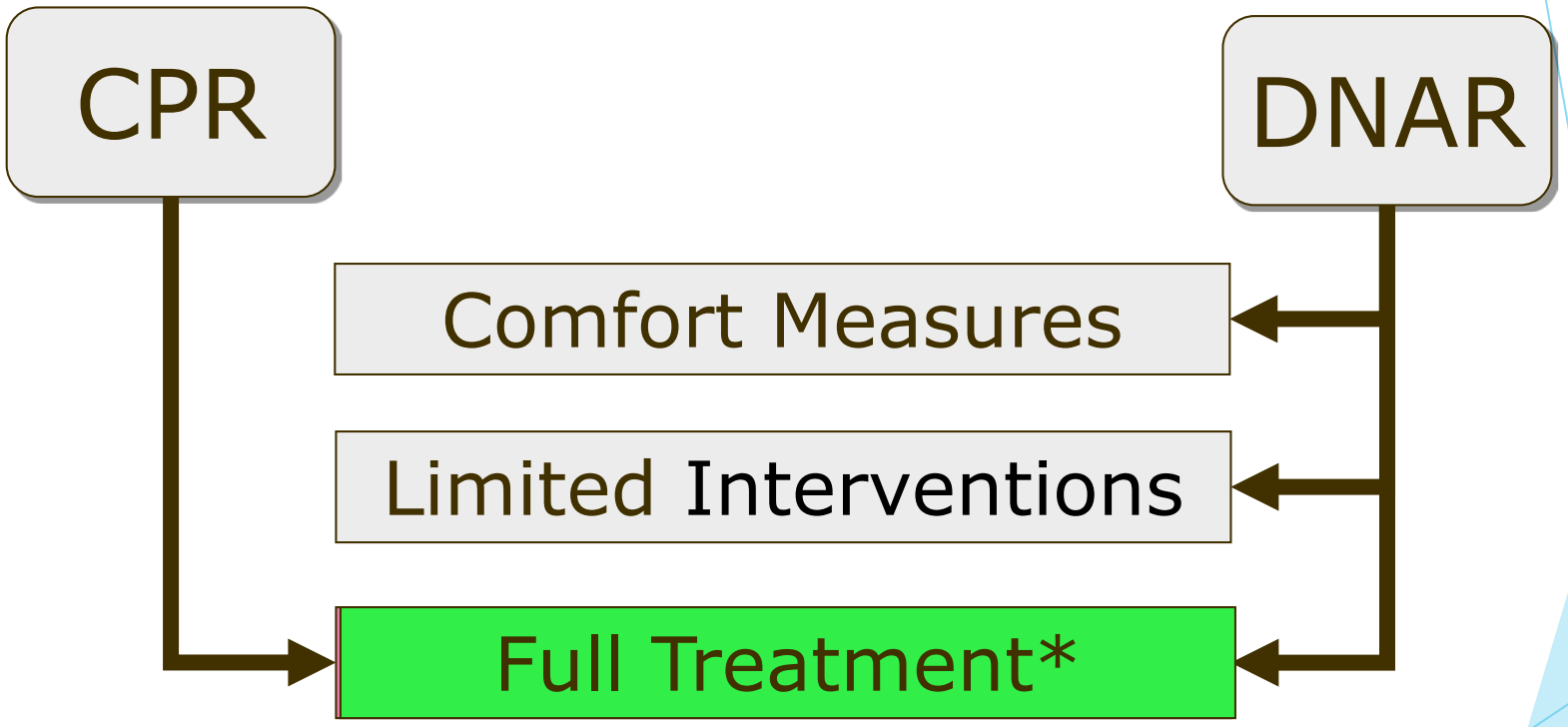
Diagram of POLST Medical Interventions



*Consider time/prognosis factors under "Full Treatment"

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

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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.

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Section D – Important Signatures!

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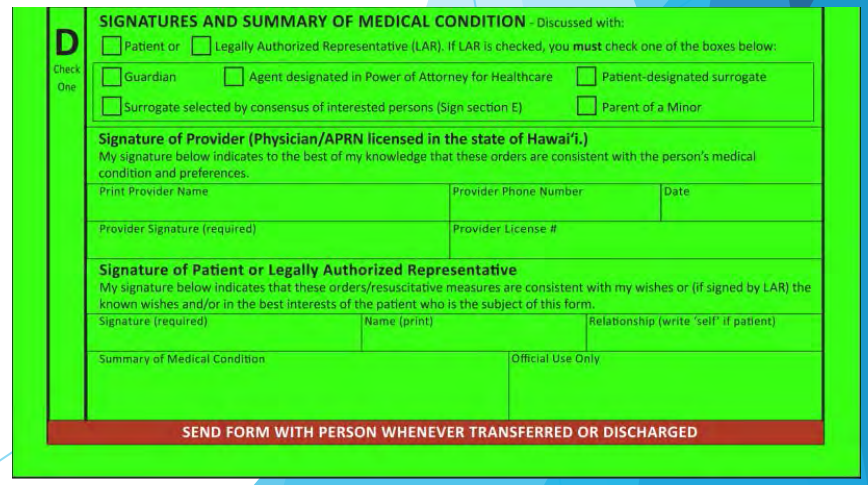
- Physician or Advance Practice Registered Nurse (APRN) **and**
- Patient **or** their Legally Authorized Representative (LAR)
- LAR - Agent designated for Health care Power of Attorney ;
  - Surrogate selected by consensus of interested persons
  - Parent of a Minor
  - Patient-designated Surrogate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

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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

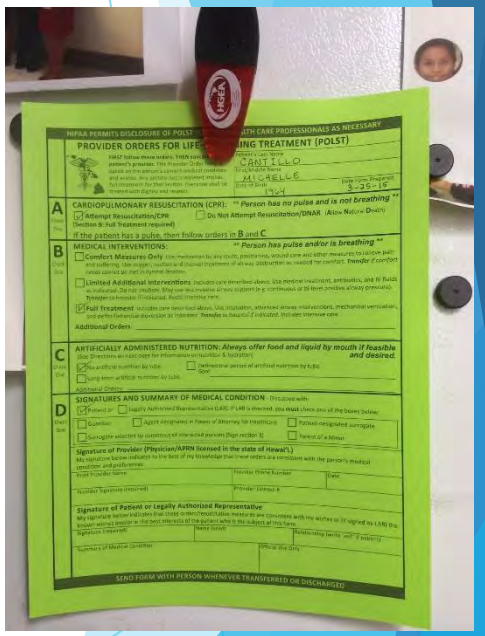
Under the Uniform Health Care Decisions Act (Chapter 327E) there are 2 types of surrogate:

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

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



The POLST Conversation

- POLST is not just a check-box form.
- The POLST conversation provides context for patients/families to:
  - Make informed choices.
  - Identify goals of treatment.

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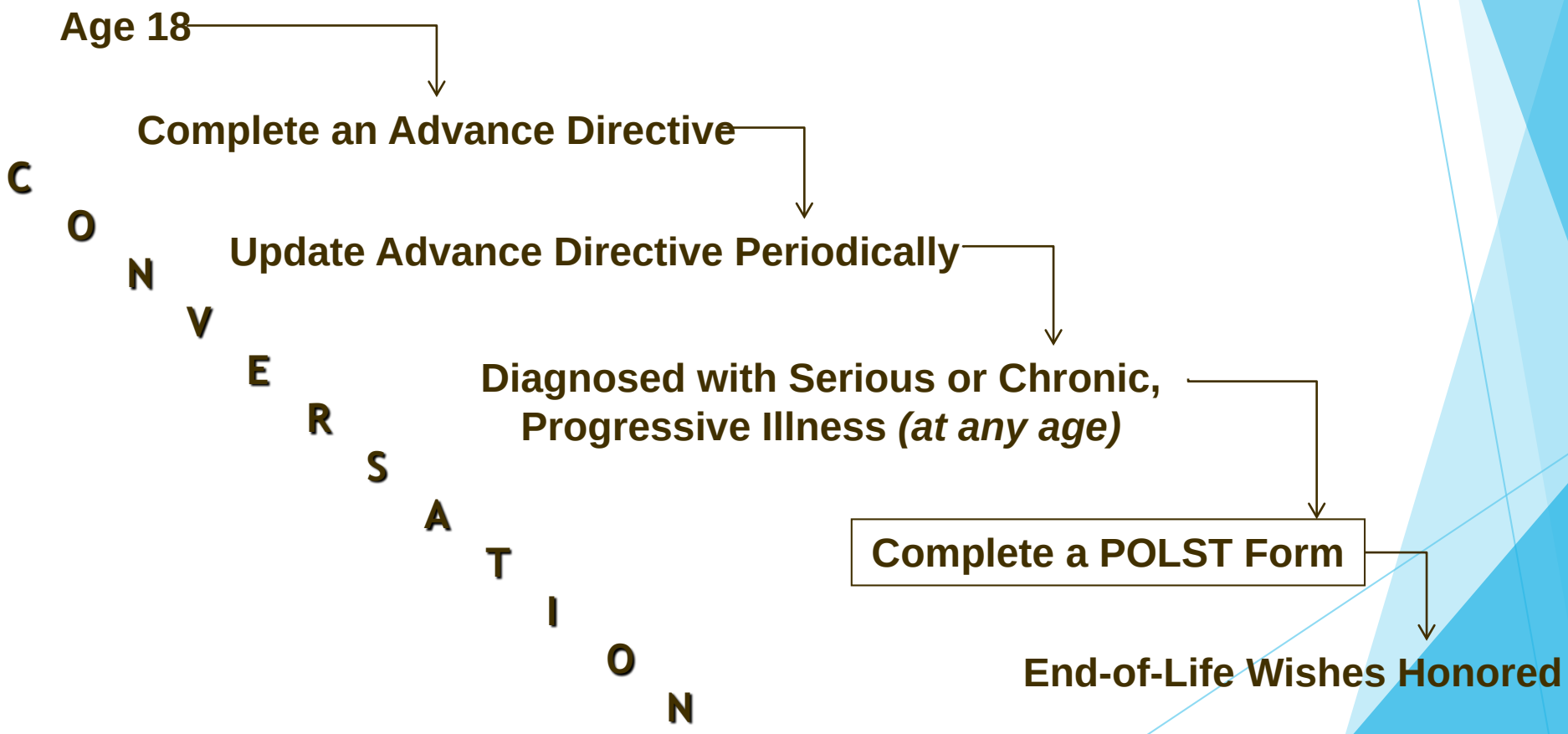
Where Does POLST Fit In?

Advance Care Planning Continuum



POLST Form

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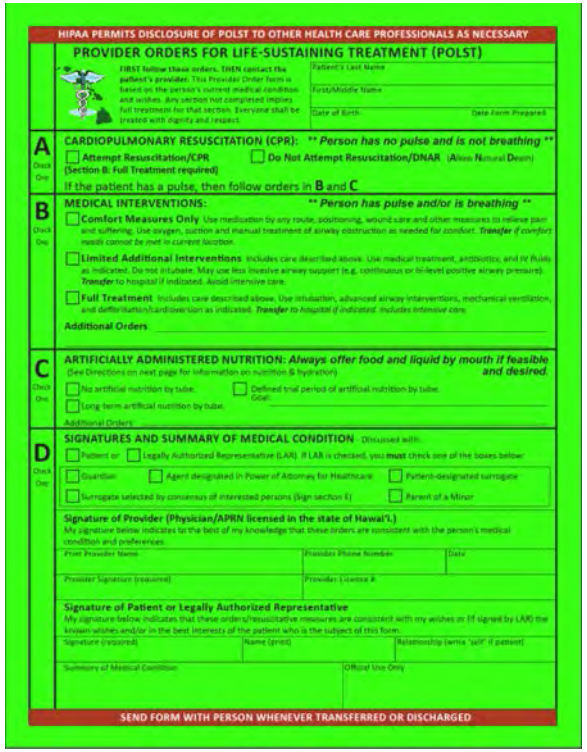
The POLST form is available from:
www.kokuamau.org/polst



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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 ☐ Do Not Attempt Resuscitation/DNAR (Allow Natural Death)
(Section B: Full Treatment required)
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:
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Signature (required) | Name (print) | Relationship (write 'self' if patient)
Summary of Medical Condition | Official Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Don’t use Tube Feeding w/ Advance Dementia

- **Don’t recommend percutaneous feeding tubes in patients with advanced dementia**
- **Instead offer oral assisted feeding**
- Careful hand-feeding is at least as good as tube-feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort.
- Food is the preferred nutrient.
- Associated w agitation, increased use of physical & chemical restraints, worsening pressure ulcers.
- **Choosing Wisely, American Ger. Society**

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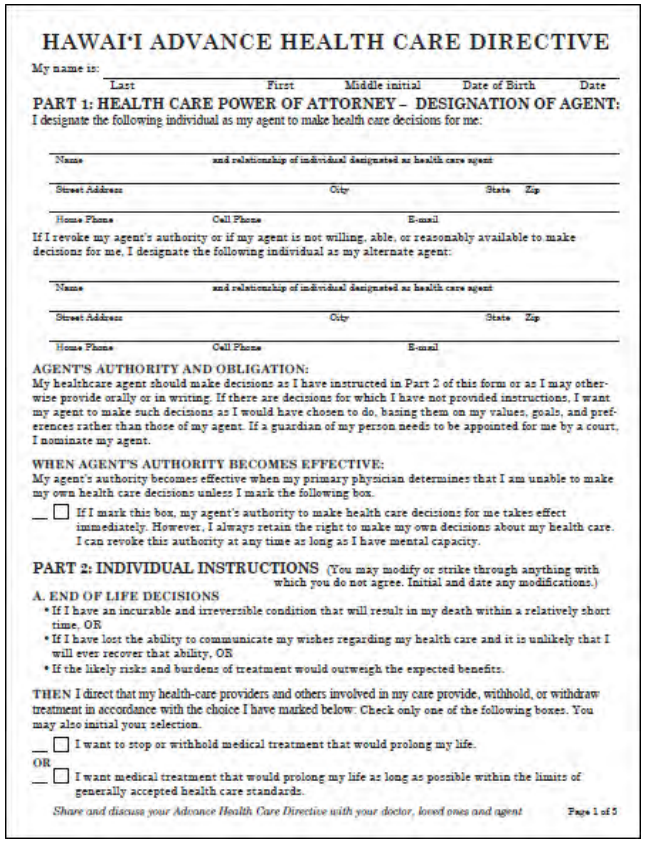
Advance Health Care Directive



HAWAI'I 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 Kōkua 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

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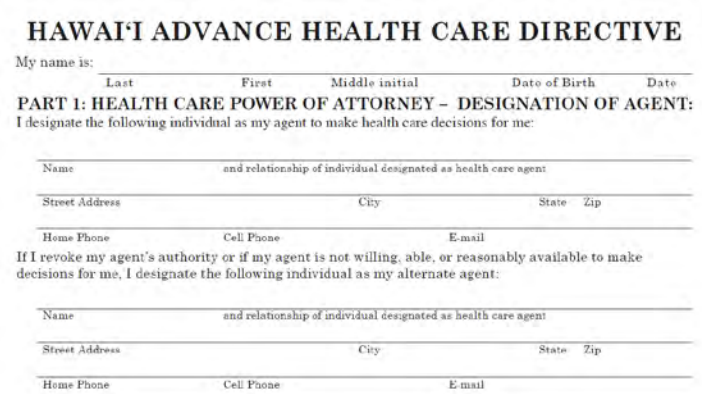
AHCD – Part 1:
Health Care Power of Attorney (HCPOA)

- 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:
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

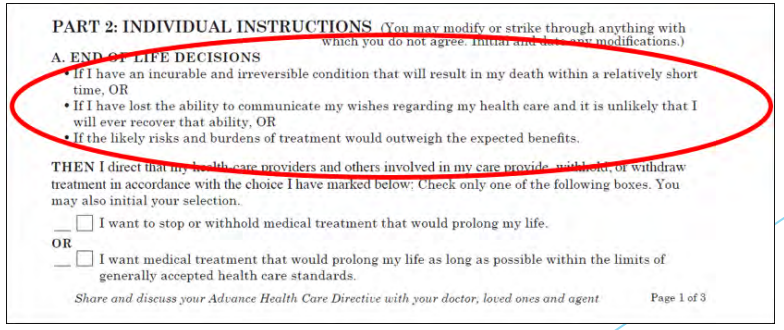
Street Address City State Zip

Home Phone Cell Phone E-mail

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

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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"

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AHCD-Part 2 Sec 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.)

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Artificial Nutrition & 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.

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Advance Directive vs. POLST

DETAILS	AD	POLST
Type of Document	Legal Document	Medical Order
Who Needs it?	All Competent Adults	Seriously Ill or frail (Surprise Question)
Treatment Focus	Future	Current
Who Completes?	Individual	Healthcare Professional
Appoints agent?	YES	NO
Guides ED decisions?	YES	YES
EMS Honors	NO	YES

the conversation project

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Join us at Kōkua Mau

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Resources and other activities

- Join Kōkua Mau Mailing List – Meetings, materials
- Download materials from the Kōkua Mau Website – look for the Event Tool Kit
- Use the new translations
- Request a speaker from Kokua Mau's **Let's Talk Story** Program – We are ready to talk with your staff, residents, family council – let us know!

Your Conversation Starter Kit

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

Using the Conversation Starter Kit at Different Stages of the Disease

- **Upon diagnosis of a condition such as Alzheimer's disease that will result in cognitive decline,** the affected person may wish to use (or be encouraged to use) the Starter Kit to identify values and facilitate conversations with chosen decision makers and other family members who are likely to wish to participate in later decisions about medical care. Appointment of a proxy and documentation of these wishes is highly recommended. As part of this phase, families and loved ones may seek more information about what to expect in later stages of dementia and what decisions they are likely to come up against.

- **In the mid-stages of the disease,** there may still be moments when it's possible to remind the person with memory loss about a prior situation of death or dying ("Remember when Mom died?" "Remember when Dad was on a ventilator?"), and reminisce about how that felt.

- **In the later stages of the disease,** when loved ones are no longer able to express their wishes, families may find it helpful to use the Starter Kit as a guide to come together to reach consensus about the values expressed in the past by the person who has memory loss. It may also be helpful to reflect on how he lived his life. Remembering family events and the values and opinions the loved one expressed in those situations can help anchor such discussions.

Resources – Cont'd

KŌKUA MAU
"Continuous Care"
Hawai'i Hospice and Palliative Care Organization

- The Starter Kit from The Conversation Project including the **Starter Kit for People with Dementia**
- ACP Decisions videos – available to any professional – 3 specifically for Dementia

  contact Robert Eubanks at HMSA
  Robert_Eubanks@hmsa.com
- Go Wish Cards or "Hello" Game

Questions?

KŌKUA MAU
"Continuous Care"
Hawai'i Hospice and Palliative Care Organization

Contact Kokua Mau

www.kokuamau.org

www.kokuamau.org/professionals/event-tool-kit

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