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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!
- Provide professional networking & training
- 3. Change the System Policy & Legislation



Kokua Mau Resources:

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







HOME

COVID-19 V

EVENTS ~

OUR SERVICES ~

RESOURCES >

FOR PROFESSIONALS ~

MEMBERSHIP ~

ABOUT ~

LANGUAGES ~

Advanced Dementia Resources and Issues

For many who have cared for someone living with dementia, it's called "the long good bye." Caregivers are grieving the loss of their loved one while they're still alive, prolonging and complicating the grief process. Often the person can linger for many years in an advanced dementia stage, immobile and unable to care for him or herself, in need of 24/7 care. At this point, because there is no cure, good palliative care improves quality of life immeasurably – having good person-centered care, love, and gentle touch.

QUICK LINKS

- Advance Care Planning
- Advance Directives
- POLST
- Let's Talk Story Program
- Palliative Care in Hawaii
- ► Hospice Providers in Hawaii

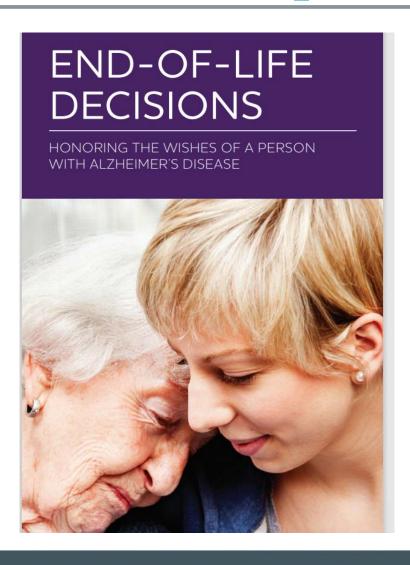


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Alzheimer's Association Resource

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-planningfor-patients-with-alzheimers-disease/

 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6 393818/



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





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







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





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 III Children
- Dementia/Alzheimer's Disease Starter Kit
- How to choose/be a health care agent

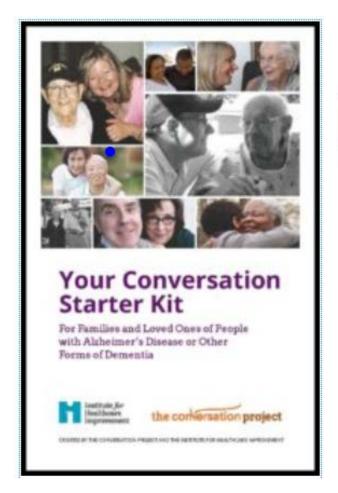






Additional Tools Available:

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





Being Prepared in the Time of COVID-19 These Things You Can Do Now This is a challenging time. There are many things that are out of our control. But there are some things we can do to help us be prepared - both for ourselves and the people we care about. Hom are three important things such of so can do, right now, to be prepared. Pick your person to be your health care YOU SHOULD KINDW decision maker National Assessed Management on the Chance a halatin care decision matter toffee brown as a print. to the property offs and points after agent, or health care proses of alternacy — a person who will make medical decisions for your Figure became too sick to make turned frittening. Stay having Class pos-fered under American company (coma final for other good, to be to consider to be a cloud to put whether Name or talk with your health case decision maker to make auto Not study with a Committee of the they know what matters must be pro-Tide concession will you decided reduces a No lease his These also de gat a server uses of 1976 I the extent of security and the a force of the limiting a selection. Now one coals of the Ribal in Same by your decision maker and one rose to your health care team. the stocked or published by the the last of text of the last deposits, and the name of the same of the Significances, Sectional States Indian College States Surveying Talk about what matters most to you falls with your important people and decision risker plant. what reatters most · The language date of the contract of the con . A particular of most constraint for innovation for the file for Makes of Michigan Coulom Payoff size Speciments in the Post America. After pix talk for prior found ones about what matters, Safé to your health care team.



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.)



The Starter Kit

Step 2 Get Set

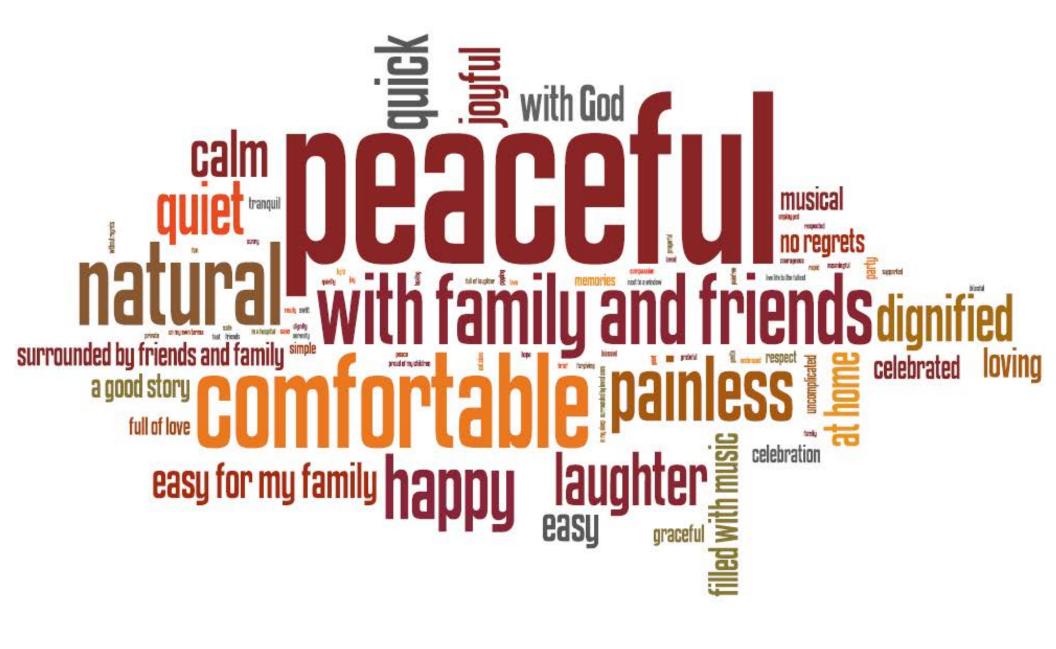
What's most important to you as you think about how you want to live at the end of your life? What do you value most? Thinking about this will help you get ready to have the conversation.

? 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.)





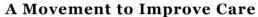














What Matters to Me...

- •"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 ill	lness, 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

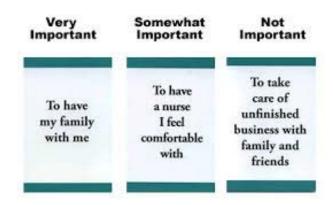
MARK ALL THAT APPLY:

? 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	
? WHEN would be a good time to ta	Other:	
 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: 	



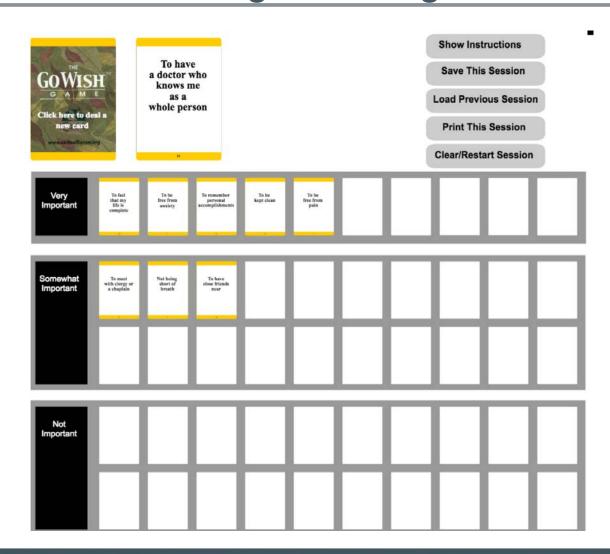
Go Wish Cards www.GoWish.org







Go Wish Digital Version www.gowish.org



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?

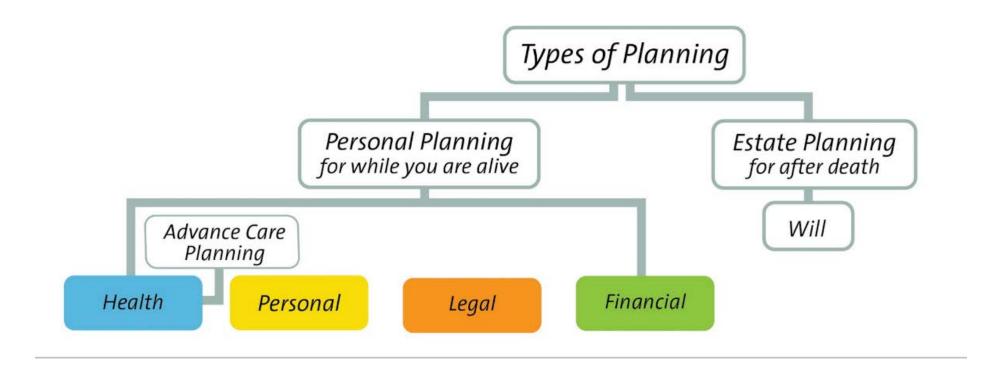


Did you know...

- 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

Last First Middle initial Date of Birth Date PART 1: HEALTH CARE POWER OF ATTORNEY – DESIGNATION OF AGEN I designate the following individual as my agent to make health care decisions for me: Name	My name is:						
I designate the following individual as my agent to make health care decisions for me: Name							Date
Name Steet Address City State Zip	PART 1: HEALTH (CARE POWER O	F ATTORNEY	- DES	IGNATION	OFA	AGEN'
Street Address	I designate the following in	ndividual as my agent t	o make health care de	ecisions f	or me:		
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Home Plane Call Plane E-mail		And a secondary	a marriage annual		are agen.		
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Name and relationship of individual designated as health care agent Street Address: City State Zep Home Plane E-mail AGENT'S AUTHORITY AND Cell Plane E-mail AGENT'S AUTHORITY AND Gold make decisions as I have instructed in Part 2 of this form or as I may other wise provide orally or in writing. If there are decisions for which I have not provided instructions, I wan my agent to make such decisions as I would have chosen to do, beaing them on my values, goals, and presences rather than those of my agent. If a guardian of my person needs to be appointed for me by a cou I nominate my agent. My agent's authority becomes effective when my primary physician determines that I am unable to mak 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 car 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 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.						to mal	ce
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Share and discuss your Advance Health Care Directive with your doctor, loved ones and agent Page 1 o	erences rather than those I nominate my agent. WHEN AGENT'S AUT MY agent's authority become your health care decis immediately. Hot I can revoke this PART 2: INDIVIDU A. END OF LIFE DEC "If I have an incurable time, OR "If I have lost the abili will ever recover that I'f the likely risks and THEN I direct that my he treatment in accordance with may also initial your selection. I want to stop or OR I want medical tr	e of my agent. If a gua: HORITY BECOME: omes effective when m ions unless I mark the k, my agent's authority wever, I always retain where it and the second of the AL INSTRUCTIO whi ISIONS and irreversible condity ty to communicate my ability, OR burdens of treatment alth-care providers and the theoloce I have me ction. withhold medical treat eatment that would pi	we chosen to do, bair dian of my person: SEFFECTIVE: Ny primany physiciar Pollowing box. To make health car the right to make m as long as I have m DNS (You may monichly ou do not agree ition that will result wishes regarding m would outweigh the others involved in murked below. Check of tement that would prolong my life as long my life as long my life as long my life as long my prolong my life as long my li	ing them needs to a determi- ne decisio ay own dental cap dify or st in my d ay health e expecte ny care pr only one of	on my values be appointed for me take scisions about acity. The through a mid date any me eath within a care and it is disensed to the following the followi	goals, for me b unable es effect my hes anythin nodificas relative unlikes d, or wit g boxes	and prey a course to make the
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Available to download on Kokua Mau Website www.kokuamau.org



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

My name is:	First	Middle initial	Date of Birth	Date
		OF ATTORNEY - It to make health care decis	DESIGNATION OF sions for me:	AGENT
Name	and relationshi	p of individual designated as h	nealth care agent	
Street Address		City	State Zip	
Home Phone	Cell Phone	E-	mail	
		it is not willing, able, or i dividual as my alternate	reasonably available to m agent:	ake
Name	and relationshi	p of individual designated as h	nealth care agent	
Street Address		City	State Zip	
Home Phone	Cell Phone	· · · · · · · · · · · · · · · · · · ·	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

		which you do not agree.	Initial and date ony modifi	ications.)
A. END OF LIF	E DECISIONS		COLUMN STREET,	
If I have an in time, OR	curable and irreversible	condition that will result	in my death within a relat	ively short
	he ability to communicat er that ability, OR	e my wishes regarding m	y health care and it is unli	kely that I
• If the likely ris	ks and burdens of treat	nent would outweigh the	expected benefits.	
THEN I direct tha	my health care provider	and others involved in my	care provide withhold, or	withdraw
treatment in accord may also initial ye		e marked below: Check or	nly one of the following bo	kes. You
_ I want to	stop or withhold medical	treatment that would pro	olong my life.	
OR				
	dical treatment that wou accepted health care star		g as possible within the lim	nits of
Share and disci	ss your Advance Health Co	are Directive with your docto	er. 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.

	LIEF FROM PAIN:
	If I mark this box, I choose treatment to alleviate pain or discomfort even if it might hasten my death.
D. OTI	HER
	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?

- Provider
- Orders for
- <u>L</u>ife
- Sustaining
- Treatment

	PROVIDER ORDERS FOR LIFE-SUSTA	INING TREATMENT (POLST)					
	FIRST follow these orders. THEN contact the patient's provider. This Provider Order form is listed on the person's current medical condition.	Patient's Cast Name First/Middle Name					
	and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.						
		** Person has no pulse and is not breathing **					
A heal one	Attempt Resuscitation/CPR Do Not (Section B: Full Treatment required)	Attempt Resuscitation/DNAR (Allow Natural Death)					
	If the patient has a pulse, then follow orders MEDICAL INTERVENTIONS:	in B and C ** Person has pulse and/or is breathing **					
B	Comfort Measures Only: Use medication by any ro	the positioning, wound care and other measures to relieve pain of sinway obstruction as needed for comfort. Transfer if comfort					
		described above. Use medical treatment, antibiotics, and IV fluids y support (e.g. continuous or bi-level positive airway pressure).					
	Full Treatment Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation and defibrillation/cardioversion as indicated. Trensfer to hospital if indicated, includes intensive core.						
	Additional Orders						
Throk One	No artificial nutrition by tube. Defined trial Oost. Oost.	period of artificial nutrition by tube.					
D	SIGNATURES AND SUMMARY OF MEDICAL CO Patient or Legally Authorized Representative (LAR).						
D hed one	SIGNATURES AND SUMMARY OF MEDICAL CO	If LAR is checked, you must sheck one of the boxes below: ney for Healthcare Padent-designated surrogate					
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POLST in Hawaii

Effective 2009, Updated 2014

1	FIRST follow these orders. THEN contact the	Patient's Last Name					
		Patient's Last Name					
	patient's provider. This Provider Order form is based on the person's current medical condition and wishes. Any section not completed implies	First/Middle Name					
	full treatment for that section. Everyone shall be treated with dignity and respect.	Date of Birth	Date Form Prepared				
A Check One	(Section B: Full Treatment required)	Attempt Resuscitation	oulse and is not breathing *1 /DNAR (Allow Natural Death)				
_	If the patient has a pulse, then follow orders i						
B Check One	MEDICAL INTERVENTIONS: Comfort Measures Only. Use medication by any rou and suffering. Use oxyger, section and manual treatment needs cannot be met in current location. Limited Additional Interventions: includes care disamination of the committee of the commi	ste, positioning, wound car of airway obstruction as ne escribed above. Use medic	eeded for comfort. <i>Transfer if comfort</i> all treatment, antibiotics, and IV fluids				
	Full Treatment: Includes care described above. Use intubation, advanced alloway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. Transfer to hospital if indicated. Includes intensive core. Additional Orders:						
One	Long-term artificial nutrition by tube. Additional Orders: SIGNATURES AND SUMMARY OF MEDICAL CO	ONDITION - Discussed w	vithe				
D	Patient or Legally Authorized Representative (LAR). If	f LAR is checked, you must	check one of the boxes below:				
One One	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 Milror						
	Signature of Provider (Physician/APRN licensed in the My signature below indicates to the best of my knowledge that condition and preferences.		nt with the person's medical				
- [Print Provider Name	Provider Phone Number	Date				
1	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 which and/or in the best interests of the patient who is the subject of this form.						
	Signature (required) Name (print)	Re	lationship (write 'self' if patient)				
	Summary of Medical Condition	Official Use Only					

	ent Name (last, first, middle)			Date of Birth		Gender	
_						M	F
	ent's Preferred Emergency Contact		presentative				
Nami	•	Address			Phone Nu	mber	
Heal	th Care Professional Preparing Form	Preparer Title	Phone No	ımber	Date	Form Pre	pared
E	SURROGATE SELECTED BY CO (Legally Authorized Representati make this declaration under the penaltitative for the patient named on this form capacity and no health care agent or cor agent or guardian or designated surroga made reasonable efforts to locate as ma lack of capacity and that a surrogate de- as the patient's surrogate decision-make and understand the limitations regarding.	we as outlined in section y of false swearing to establi in. The patient has been dete urt appointed guardian or pa- ite is not reasonably available in interested persons as pra- islon-maker should be select er in accordance with Hawai!	n D) sh my authority is mined by the prisent-designated at the primary platficiable and has defor the patier Revised Statute:	to act as the le imary physicia surrogate has sysician or the informed such st. As a result I s §327E-5. I ha	in to lack di been appo physician's persons of have been ave read se nd nutrition	ecisional inted or the designee the patie selected ction C be n.	hes has nt's to act
	Signature (required)	Name			Relationsh	hip	
Se	patient or the patient's legally authorize blue of original form is strongly encourage ing POLST • Any incomplete section of POLST implie sction A: • No defibrillator (including automated ex "Do Not Attempt Resuscitation." sction B: • When comfort cannot be achieved in the	ged. Photocopies and FAXes on is full treatment for that sect sternal defibrillators) should be current setting, the person	Verbal orders by if signed POLST f ion. be used on a per including some	providers are orms are legal son who has c	not accept and valid. hosen	able.	
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Se Se Revitis	• Use of original form is strongly encourage POLST • Any incomplete section of POLST implies inction A: • No defibilition (including automated encourage) • No defibilition (including automated encourage) • No defibilition (including automated encourage) • When confort cannot be achieved in the best considered to a setting able to provide be transferred to a setting able to provide a provide a provider with the provider and the part physician certify in the patients medical prolonging the act of dying and the part vicewing POLST • The prison is transferred from one care. There is a substantial change in the pensive them to the proposition of the provider and the part of the proposition of the provider and the part of the proposition of the provider and the part of the proposition of the pro	of representative to be valid. If the state of the state	Verbal orders by if signed PDIST I is signed PDIST I is signed PDIST I including some (a hip fracture), the used on a per including some (a hip fracture), the hip signed is signed as a signed as a trial casted by consensation of or "Full Treatm grading artifacture), when the primary continuation of any neurological ended when: er, or presentative, can accept the properties of the propert	providers are orms are legal son who has c one with "Com Comfort Meas ent." Inutrition or has so finteresty physician an artificial nutri response in the na so to this che VOID' in large at the common that are to the common to the common to to the common to the common the common to the common the	not accept and valid. hosen fort Measu tures Only," ydration. He d persons d a second tion or hyd he future. H	able. Jowever, a j may only independing traden is rest. \$3276 tment plait the origin.	shoul make ent nerely 5.



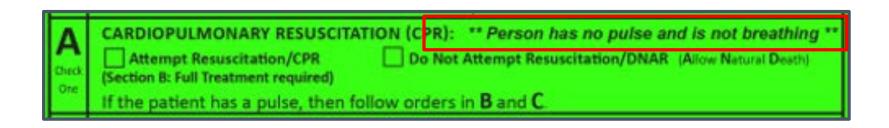
HI POLST Form – Information

HIPAA PER	RMITS DISCLOSURE OF POLST TO OTHER	HEALTH CARE PROFESSION	ONALS AS NECESSARY
PROV	IDER ORDERS FOR LIFE-SUSTA	INING TREATMEN	Γ (POLST)
3	FIRST follow these orders. THEN contact the patient's provider. This Provider Order form is	Patient's Last Name	
	based on the person's current medical condition and wishes. Any section not completed implies	First/Middle Name	
	full treatment for that section. Everyone shall be treated with dignity and respect.	Date of Birth	Date Form Prepare

HIPAA PERMITS DISCLOSURE OF	POLST TO OTHER HEA	LTH CARE PROFESSION	NALS AS	NECESSARY
Patient Name (last, first, middle)		Date of Bir	rth	Gender M F
Patient's Preferred Emergency Contact of	or Legally Authorized Re	presentative	Phone	Number
Health Care Professional Preparing Form	Preparer Title	Phone Number		Date Form Prepared
	The second secon	Alexandria Comment		



Section A: Cardiopulmonary Resuscitation (CPR)



Person has no pulse and is not breathing



Section B: Medical Interventions

В	MEDICAL INTERVENTIONS:	** Person has pulse and/or is breathing **
Dock One	Comfort Measures Only Use medication by a and suffering. Use daygen, suction and manual treat needs connot be met in current location.	ny route, positioning, wound care and other measures to relieve pain ment of airway obstruction as needed for comfort. Transfer if comfort
		care described above. Use medical treatment, antibiotics, and IV fluids airway support (e.g. continuous or bi-level positive airway pressure). t.
	Full Treatment Includes care described above. L and defibrillation/cardioversion as indicated. Transfe	Ise Intubation, advanced airway interventions, mechanical ventilation, er 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

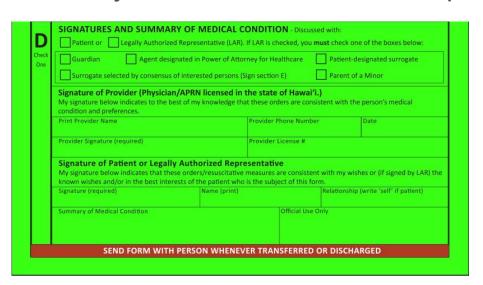
C	ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and light (See Directions on next page for information on nutrition & hydration)	quid by mouth if feasible and desired.
Check One	No artificial nutrition by tube. Long-term artificial nutrition by tube. Additional Orders: Defined trial period of artificial nutrition by Goal:	tube.

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





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

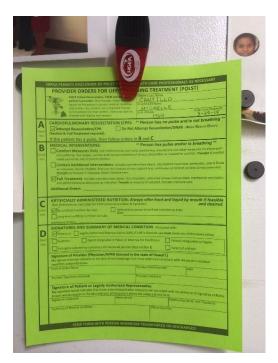
- Section E only needs to completed if the patient lacks capacity and has not designated a health care power of attorney
- Non-Designated Surrogate: This individual is appointed in accordance with HRS 327E, & has limitations placed upon him or her with respect to decisions about withholding or with-drawing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

Е	SURROGATE SELECTED BY CONSENSUS (Legally Authorized Representative as outling I make this declaration under the penalty of false swell tative for the patient named on this form. The patient capacity and no health care agent or court appointed agent or guardian or designated surrogate is not reasonable reasonable efforts to locate as many interested lack of capacity and that a surrogate decision-maker as the patient's surrogate decision-maker in accordant and understand the limitations regarding decisions to	ned in section D) earing to establish my authority to act as the legating to establish my authority to act as the legatina been determined by the primary physicial guardian or patient-designated surrogate has lonably available. The primary physician or the persons as practicable and has informed such should be selected for the patient. As a result Ince with Hawai'l Revised Statutes §327E-5. The	n to lack decisional been appointed or the physician's designee has persons of the patient's have been selected to act ove read section C below
	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





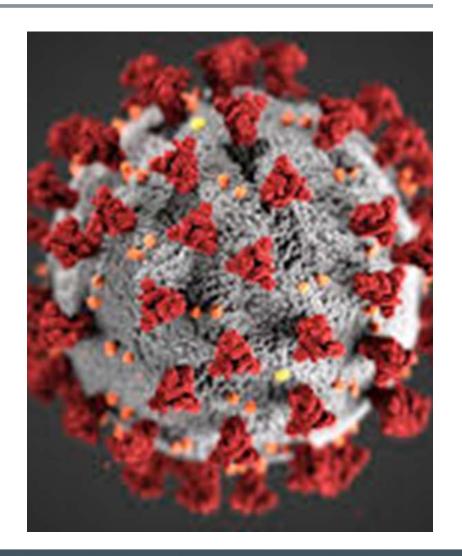
Who Would Benefit from Having a POLST Form?

- Chronic, progressive illness
- Serious health condition
- Medically frail
- A person for whom you would issue an inpatient 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

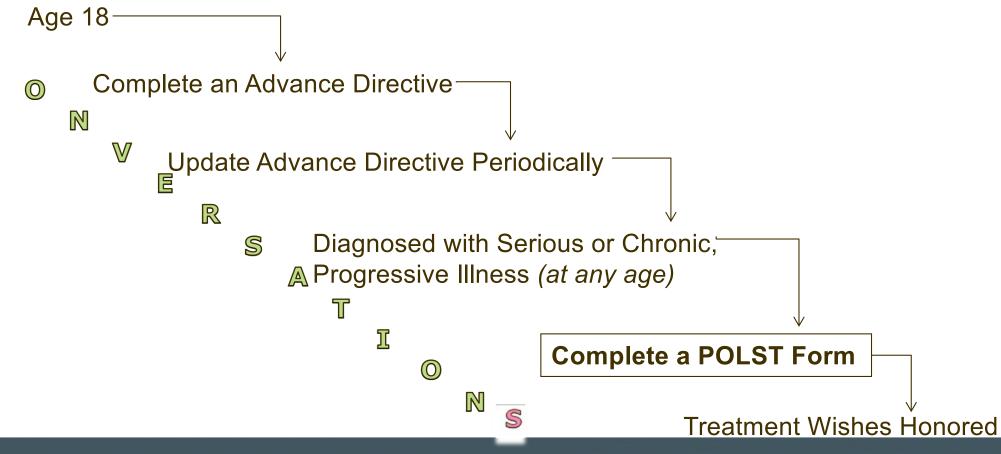
not everyone needs a

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
Oʻahu:	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 80	00-458-4600 #300	808-532-4006



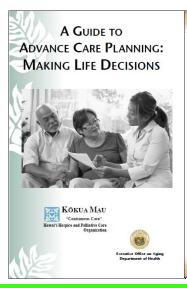
Join Us at Kōkua Mau!!

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







It is your eift to loved ones, family members and friends so that they won't have to guess what you want if you no longer can speak for yourself



HAWAI'I ADVANCE HEALTH CARE DIRECTIVE

My name 15:
Last First Middle initial Date of Birth Date
PART 1: HEALTH CARE POWER OF ATTORNEY - DESIGNATION OF AGENT:

Street Address

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:

Other

ORDER TO SHARK AND OBLIGATION:
My healthcar agent should make decisions as I have instructed in Part 2 of this form or as I may otherwise provide earlies in switzing. If there are provided instructions, I want may great to make such decisions as I would have choose to do, braing them on my values, pash, and preferences rather that althour of my agent it againstant of my promote meets to be applicated for me by a countries from the provided from the provided for meets to the past of meets and the provided for meets to the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the past of meets and the past of meets are the p

WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE:

WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE:
Why aper's attentive because efficitive when my primary physician determines that I am unable to make my own health care decisions unless I mark the following ben.

— I start and the box my agent's authority to make health care decisions for me takes effect manufactured. However, I always retain the right to make my own decisions about my health care. I can resolve the unstelling parties are long as I shaw mental quarter.

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

A first our last is deschaffered.

If I have an incombine and irreversible condition that will result in my death within a relatively short time, OR

If I have a located and 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 inta 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 dactor, loved ones and agent Page 1 of 5

Being asked to make a decision about cardiopulmonary resuscitation (CPR) can be complicated. Few of ut have ever seen CPR performed. Our understanding of CPR may come from what we see on TV, where it look easy and seem to be very successful without any complications. Unfortunately, these TV images of CPR are not completely accurate.

Kokua Mau - Hawai'i Hospice and Palliative Care Organization

CPR is a longer process than most people realize. It is an attempt to re-start the heart when the heart has stopped beating.

The person is placed on a hard board or on the ground and the center of the chest is pushed in about 1.5 to 2 inches. These chest compressions must be done 100 times each minute. Artificial must be done 100 times each minute. Artificial respiration using a special mask and bag over the person's mouth to pump air into the lungs may be started. When the emergency team arrives, a breathing tube may be inserted into the windpipe to provide oxygen, and a number of electrical shocks may be given with paddies that are placed

reatments, the person is taken to the emergency department. Those who survive will then be transferred to the intensive care unit at the hospital and attached to a ventilator (breathing machine)

Kōkua Mau

Care Organization

Risk factors that are more frequent among older persons may contribute to lower chances of CPR survival as age increases. Most older adults do not have the type of heart rhythm that responds to or the view of the control of the co

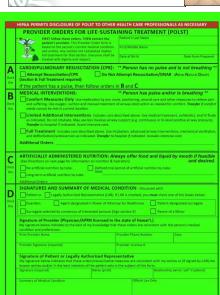


Kōkua Mau - Hawai'i Hospice and Palliative Care Organization

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A GUIDE FOR DECISION MAKING

A GUIDE FOR DECISION MAKING



SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

A Provider's Guide to POLST (Provider Orders for Life-Sustaining Treatment) Maintained for Hawai'i by Kökua Mau **Continuous Care** | Continuous Care** | Continuous



What is POLST?

POLIT [Provider Totales for Life-outsiding Treatment] is a radial order that give prices now control control in the size is prodict to legal characters that yet includes the size price in control prices and the product of the provider and prices are provider and patient, reading patients to make prices and prices are provider and patient, enabling prices and patient, reading patients to make more intermed existion. The POLIT from connects took exclusion is clear manner and one patient prices all providers, including first responsers and emergency medical services (BAI) personnel. As a result, the patients whose can be homored account a stringly of care.

Is the POLST simply a DNR order?

No, POLET is a document that empowers a patient or their legally authorized representative (see below) to make decisions along the whole conditionant orace, now very aggressive, life sustaining care, to comfort care only, including choices about full resuscitation or do not attempt resuscitation.

Is POLST the same as an Advance Health Care Directive?

No, POLST does not replace an Advance Health Care Directive (AHCD). The AHCD can provide significantly more detail about an individual wishes and preference for treatment. In addition, the AHCD is the most common mechanism for designating a legally authorized representative decision maker for the patient.

Will the CCO-DNR Bracelet still be honored by EMS?

Why is the POLST form lime green?

The POLST form is usually completed on a distinctive bright time-green form, but is also freely available from the internet (at www.kstumam.org/poto) and or is conceptable in loads and white. The bright color is to make the form quicity visible to thinlike and emergency medical services personned. The time-green color is also easily copied. A copy on white paper is a valid document.

Does the POLST form travel with the patient between settings of care?

The contract from the segged to the contract from the patient between settings of care?

The contract from the segged to the contract from the contract from the segged to yet a present across the state. As a tight from the contract from the contra

Its implementing the orders from the POLST form protected under Hawai'i Law?
Yes. The law states that no provider will be subject to criminal prosecution and civil fiability for carrying out the treatment orders in good falsh or for performing cardiopulmonary resuscitation? If the person performing CPV was unaware of the POLST order to not betterpt resuscitation or they believed that the treatment orders (including the DNR order) had been

How do providers get more copies of the POLST form?

The form is available on the Kibus Mass was size (www.kokusmasu.org/polst) in POF format for easy replication. It is the standard that the form be on an Six* X.1.* sheet of time colored paper. The form must have both sides copied on the front and back of the page.

Where is the family encouraged to keep the form? For the patient at home, the POLIT form should be kept in a place readily accessible by family members. Examples include o entingeration, in the medicine cashine, on the back of a dedorsom door or on a beddiet table. It should be kept with the AHCO.

What is POLST? Provider Orders for Life-Sustaining Treatment A Consumer Guide to POLST

• POLST = Provider Orders for Life-Sustaining Treatment, is your

You use POLT when you have a serious health condition.
 Sool winders, nursed and other healthcare professionation help you fill out your own POLT form, but it MUST be signed by your physician or APRN in order to be valid.
 POLTS contains medical orders indicating what medical care you want or good want or you become unable to make the decisions yourself.
 Your doctor or APRN, who is iterated in the State of Hewari (or slowed to

The POLIST form is intended for a person who has a chronic debilitating illness or is facing a life limiting disease, such as end-stage lung or heart disease or a terminal cancer.

The decision to create a POLIST should be discussed with each person's own provider.

The POLST form asks for information about your preferences for medical treatment

FREQUENTLY ASKED QUESTIONS (FAQ)

How do I get a copy of the POIST form?

Two who I get a copy of the POIST form?

Two who I get a copy of the POIST form?

Two who I get a copy of the POIST form?

Two who I get a copy of the POIST form and instruction to provide the I get a copy of the I get a copy

Does the law require that I complete a POLST?

Dues our leave require client is Completed a POCS1: No. POCST is voluntary and has been available in Hawaif since July 2009. However without a POLST, Emergency Medical Services [BMS] or other healthcare providers may be required to attempt to restart your heart and breathing should they stop, even if you do not wish an attempt to be made to resurciste you, and would prefer to die a natural death.

Where is the POLST form kept? If you've the none you should kept the original line green POLST form in a location where it can easily be seen. The local pince is on your retrigerator where BMS personnel will sole for it first. Other visible pieces could be the beat of the bedroom docu, on a beloak clab, or in your medicial cable, if you you retrigerator have likely out POLST form may be kept in your medicial chart along with other medicial pricers. A copy of your POLST form on white paper is tigat.

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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



Kokua Mau Contact

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808-585-9977
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hope@kokuamau.org
808-221-2970

www.theconversationproject.org









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!

