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Update from Kōkua Mau: Advance Care Planning and Dementia

August 29, 2017
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Executive Director
Who is Kōkua Mau?

- 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

- 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
Let’s Talk Story - Continued

► 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

- 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!!
What is POLST?

- Provider
- Orders for Life
- Sustaining Treatment
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
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
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
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?”
POLST in Hawaii

- One form for entire state.
- Use not mandated.
- **Honoring form is mandated.**
- Provides immunity from civil or criminal liability.
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
**Person has no pulse and is not breathing**
Section B: Medical Interventions

**Person has pulse and/or is breathing**
Diagram of POLST Medical Interventions

- CPR
- DNAR

- Comfort Measures
- Limited Interventions
- Full Treatment*

*Consider time/prognosis factors under “Full Treatment”

“Defined trial period. Do not keep on prolonged life support.”
Always offer food and liquid by mouth if feasible and desired.

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.
☐ Long-term artificial nutrition by tube.
Goal:

Additional Orders:
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;
  - Surrogate selected by consensus of interested persons
  - Parent of a Minor
  - Patient-designated Surrogate
  - 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 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.
Where Does POLST Fit In?

Advance Care Planning Continuum

- Age 18
- Complete an Advance Directive
- Update Advance Directive Periodically
- Diagnosed with Serious or Chronic, Progressive Illness (*at any age*)
- Complete a POLST Form
- End-of-Life Wishes Honored
The POLST form is available from: www.kokuamau.org/polst
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
Advance Health Care Directive

Available to download on Kōkua 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
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
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”
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 & 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.
## Advance Directive vs. POLST

<table>
<thead>
<tr>
<th>DETAILS</th>
<th>ADVANCE DIRECTIVE (AD)</th>
<th>POLST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of Document</td>
<td>Legal Document</td>
<td>Medical Order</td>
</tr>
<tr>
<td>Who Needs it?</td>
<td>All Competent Adults</td>
<td>Seriously Ill or frail (Surprise Question)</td>
</tr>
<tr>
<td>Treatment Focus</td>
<td>Future</td>
<td>Current</td>
</tr>
<tr>
<td>Who Completes?</td>
<td>Individual</td>
<td>Healthcare Professional</td>
</tr>
<tr>
<td>Appoints agent?</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>Guides ED decisions?</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>EMS Honors</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>
Join us at Kōkua Mau

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!
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

- 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?

Contact Kokua Mau
www.kokuamau.org
www.kokuamau.org/professionals/event-tool-kit

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