

KŌKUA MAU

The Evolution of Hospice and Palliative Care in Hawaii

Linda M. Axtell-Thompson, MBA, MA
Hawaii Medical Service Association | Kokua Mau
Honolulu, Hawaii | November 10, 2011

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Meaning, Mission, Vision



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Our Meaning

kōkua = care, help, aid, assistance, relief
mau = continuous, always, steady, ever
kukui = lamp, torch, enlightenment, medicinal



Our Mission



To weave a lei of caregiving and support so the people of Hawaii facing serious illness can live in the place of their choice, with relief of pain and suffering, and according to their values, beliefs and traditions

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Our Vision



A community where the people of Hawaii are treated with dignity, compassion and love throughout their lives

Source: Field & Cassel, Approaching Death (IOM 1997)

Our Model



"Whole community approaches to end-of-life care would include a mix of programs, settings, personnel, procedures, and practices that extend beyond health care institutions and policies to involve entire communities." - IOM 1997

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Source: Field & Cassel, Approaching Death (IOM 1997)

Our History

- 1998 – Governor’s Blue Ribbon Panel on Living & Dying with Dignity
- 1999 – RWJF Community-State Partnership Grant (3 years)
- 2001 – Innovations in American Government Award
- 2002 – Moved oversight from Governor’s EOA to HIHO
- 2004 – Rallying Points Community Coalition Award
- 2007 – Merged with HIHO 501c3 nonprofit
- 2008 – MBA student project on sustainability
- 2009 – Modified to nonprofit membership model

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Our Members

▪ **Original RWJF Partners**

Governor’s Executive Office on Aging
University of Hawaii Center on Aging
Hawaiian Islands Hospice Organization
St. Francis Ethics Center

Organizational Members

Hawaii Medical Service Association
University Health Alliance
Executive Office on Aging

Individual Members

19 in 2009, 36 in 2010, 43 in 2011

Hospice Members

Bristol Hospice
Hospice Hawai’i
Hospice of Hilo
Hospice of Kona
Hospice Maui
Islands Hospice
Kaua’i Hospice
North Hawaii Hospice
St. Francis Hospice

Hospital Members

Queen’s Medical Center
Hawaii Pacific Health (4 hospitals)
Castle Medical Center
North Hawaii Medical Center

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Today & Future

Who we are:

- A statewide non-profit community benefit membership organization to promote excellence in hospice, end-of-life care, palliative care and early advance care planning
- Half-time executive director, volunteer board, and dues membership

What we do:

- Public and professional education
- Professional and organizational capacity building
- Advocacy and public policy
- Statewide leadership
- Collaboration among members and community

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Activities & Achievements



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Public & Professional
Education

- Internet site
- eNewsletter
- Educational materials
- Educational events
- Speakers bureau
- National trainings
- Medical curriculum
- Nursing curriculum
- Public health curriculum
- LTC staff training
- Educational events

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Home-Based Palliative Care
for Underserved in Hawaii

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Volume 13, Number 4, 2010
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DOI: 10.1089/jpm.2009.0216

Home-Based Palliative Care Services
for Underserved Populations

Ritabelle Fernandes, M.D., M.P.H.,¹ Kathryn L. Braun, Dr. P.H.,² Joseph Ozawa, Ph.D.,³
Merita Compton, M.P.H.,⁴ Crisanta Guzman,⁵ and Emese Somogyi-Zalud, M.D.⁶

“Conclusion: Data on outcomes and quality indicators of HBPC programs are scant, especially among immigrant Asian and Pacific Islanders patients. Our experience demonstrates the effectiveness of palliative care approaches in this population.”

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primary caregivers were enrolled. Data were collected prospectively, upon admission, and repeatedly thereafter, using the MOSCOW-VITAS Quality of Life Index, the Edmonton Symptom Assessment Scale, and the Palliative

Inpatient Palliative Care for Asian/Pacific in Hawaii

ARTICLE IN PRESS

Vol. ■ No. ■ ■ ■ 2011 *Journal of Pain and Symptom Management* ■

Original Article

Hospice Referrals and Code Status: Outcomes of Inpatient Palliative Care Consultations Among Asian Americans and Pacific Islanders with Cancer

Christina L. Bell, MD, MSc, Meiko Kuriya, MD, and Daniel Fischberg, MD, PhD
Department of Geriatric Medicine (C.L.B., D.F.), John A. Burns School of Medicine, University of Hawaii, Honolulu, Hawaii; Department of Palliative and Supportive Care (M.K.), Sorei Mitsuhashi General Hospital, Shizuoka, Japan; and Pain and Palliative Care Department (D.F.), The Queen's

"Conclusion: Consultation intensity was the strongest predictor of hospice referrals and code status changes and reduced the ethnic variations associated with hospice referral."

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racial differences in end-of-life care.
Objective. To compare cancer patients' hospice referrals and code status

Hospice and Palliative Care Organization - Kokua Mau - Windows Internet Explorer

www.KOKUAMAU.org

KOKUA MAU
"Continuous Care"
Hawaii Hospice and Palliative Care Organization

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ADVANCED DIRECTIVES

JOIN KOKUA MAU

Donate Now
Secure donations through a secure network for good.

Watch a video clip

Kokua Mau: Hawaii's Hospice and Palliative Care Organization


Kokua Mau is Hawaii's hospice and palliative care organization, and it is comprised of individual and organizational champions and supporters from hospitals, education, consumers, insurance, long term care and hospices.

We hope that you will find all the Hawaii focused information and resources on [hospice](#), [palliative care](#), [end-of-life care](#) and advance care planning you need for yourself, your loved ones and your friends.

If you are a healthcare professional, we also have educational resources, referral information and statewide activities listed under "For Professionals"

- Quick Link: [Hospices and Palliative Care providers with phone numbers](#)
- Lists of [Palliative Care Resources for Hawaii](#) compiled by Kokua Mau (2-page PDF)
- **POLST** or Physician Orders for Life Sustaining Treatment is law in Hawaii since 2009. For Providers: download the Hawaii POLST Form and to [learn more](#)
NEW: A Consumer Guide to POLST for Hawaii

CULTURAL ISSUES IN END-OF-LIFE DECISION MAKING

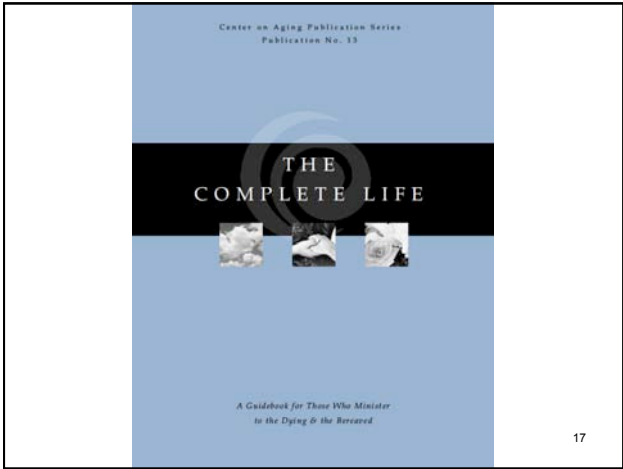


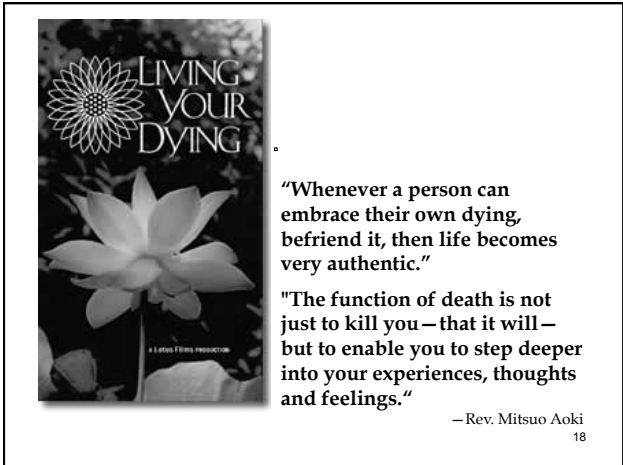
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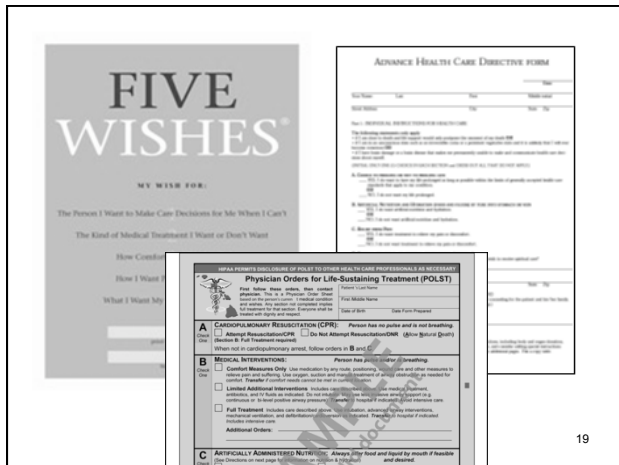
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Image courtesy of Braun, Pietsch, and Blanchette









Capacity Building

Palliative Programs

- 0 in 1998, 6 in 2011, others in development

Palliative Physicians

- 0 in 1998, 20+ in 2011

Palliative and Hospice Nurses

- 30+ RNs in 2011; plus APRNs, CNAs, LPNs

Hospice Usage

- Admissions: 1363 in 1998, 2673 in 2008, up 2x
- Average daily census: 175 in 1998, 452 in 2008, up 2.5x
- Average length of stay: 46.8 in 1998, 51.2 in 2008

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Advocacy & Public Policy

- 1999 – Hospice Reimbursement Act
- 1999 – Uniform Health Care Decisions Act, modified
- 1999 – Advance Health Care Directive Act, amended 2004
- 2002 – Controlled Substance Act
- 2004 – Pain Patient's Bill of Rights, amended 2008
- 2006 – Rapid Identification Documents Act
- 2007 – Emergency Dispensing of Controlled Substances
- 2009 – Physician Orders for Life Sustaining Treatment Act

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Collaboration & Leadership

- National Organizations
- Aging Network
- Cancer Community
- Dementia Task Force
- Medical School
- Palliative “Pupus” Events
- EOL Data Committee

Nursing Home Palliative Care



Launching POLST in Hawaii

A Provider's Guide to POLST
(Physician Orders for Life-Sustaining Treatment)
Provided for Hawaii by Kokua Mau

What is POLST?
POLST (Physician Orders for Life-Sustaining Treatment) is a document under the law that gives patients more control over their medical care. It specifies the type of treatment that a patient wishes to receive towards the end of the life cycle. POLST forms encourage communication between healthcare providers and patients, enabling patients to make more informed decisions. The POLST form documents these decisions in a clear, simple and easily understood form of directions, including the completion and emergency medical services (EMS) and the patient's wishes can be honored across all settings of care.

Is the POLST simply a wish card?
No. POLST is a document that requires a patient or their surrogate to make decisions about the whole continuum of care from aggressive life-sustaining care to comfort care only, including those that are not reversible. It is not a wish card.

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 a signature, consent of those that stand behind a patient's wishes and a statement of intent. POLST is a form that is used to document a patient's wishes and a statement of intent. It is not a wish card.

Why the POLST form is so great
The POLST form is a simple, easy-to-use form that can be used in any setting. It is a form that can be used to document a patient's wishes and a statement of intent. It is not a wish card.

Does the POLST form travel with a patient?
Yes. The POLST form is designed to be a portable form that can be used in any setting. It is a form that can be used to document a patient's wishes and a statement of intent. It is not a wish card.

Is implementing the orders from the form
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**Frequently Asked Questions
A Consumer Guide to POLST**
Provided for Hawaii by Kokua Mau

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Pacific Islands Palliative Care



Benefits, Challenges, Lessons



Benefits

- Swift, cohesive communication, one voice
- Benchmarking, sharing best practices
- Diversity of disciplines, collection of strengths
- Professional development

*“Kokua Mau fundamentally influenced our professional development over the past decade. None of us would be who we are or have the skill set we have without it.”*²⁷

Challenges

- Education and outreach never end
- Resources are limited
- Need individual and institutional commitment
- Expect constant testing and stretching

“What we stand for and how we come together is going to get really tested in the next few years with the growth of the field and the changes in health care.”

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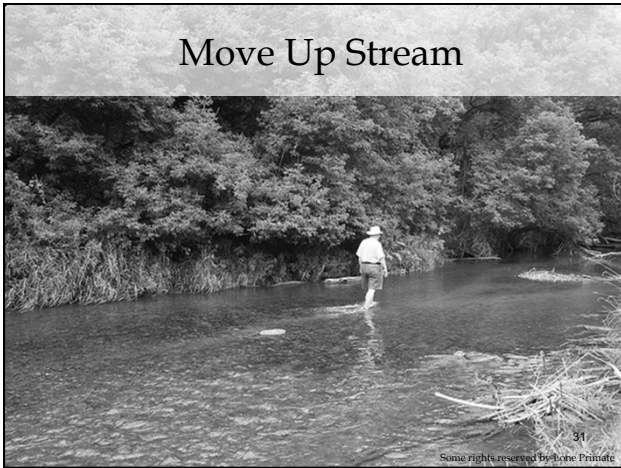
Lessons Learned

“Kokua Mau is a test of the interdisciplinary approach, working beyond our own silos.”

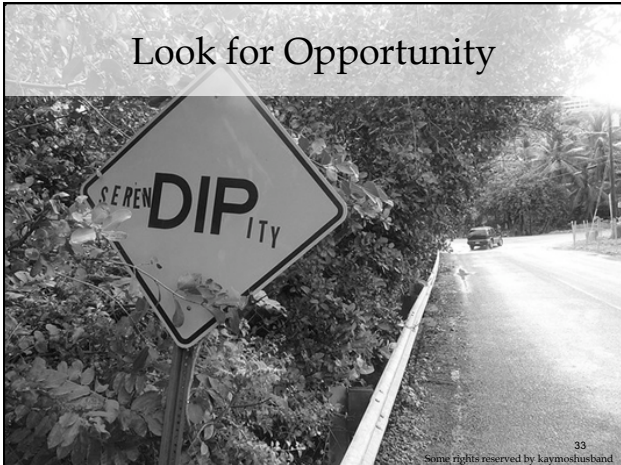
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Collaboration is Key















Our Mission



To weave a lei of caregiving and support
so the people of Hawaii facing serious illness
can live in the place of their choice,
with relief of pain and suffering, and according
to their values, beliefs and traditions

Courtesy: Hawaii Travel Authority/ Ter Johnson
