Date: Thursday, March 4, 2004

To: Representative Eric Hamakawa, Chair
Judiciary Committee

From: Kenneth Zeri, RN, MS
President & CPO
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Subject: Testimony in opposition to HB 862, "Death With Dignity" relating to the legalization of physician assisted suicide

Hospice Hawaii adamantly opposes the adoption of HB 862, legalizing physician-assisted suicide.

Discussion:

First and foremost it is critically important to acknowledge the importance of this issue. Both opponents and proponents of legalizing Physician Assisted Suicide (PAS) agree that all persons facing the end of life should be afforded the ability to live the life of their choosing as they are capable and that they should be free from pain and suffering to the level they desire. Indeed, the mission statement of Kokua Mau, a community-state partnership to improve the end of life care for Hawaii's dying and their families is: "Weaving a lei of community support so that Hawaii's people may die in a place of their choice, free from pain and suffering and treated according to their beliefs and values." The debate on PAS highlights the importance of continuing the work of Kokua Mau and other committed groups to improve end-of-life care in Hawaii.

The campaign to improve end-of-life care should be a campaign of hope, not one that says that there is no hope. The campaigns on this issue are loaded with many inflammatory words. And I truly believe that all those "words" confuse the public about the reality of the issue.

Examples of those words are "Death with Dignity" or "Aid in Dying." These phrases are meant to soften the real impact of the issue, which is to let your doctor help you kill yourself. These words and the sound bites that accompany them suggest that there is no possibility for dying a dignified death or get aid while one is dying without your doctor giving you a handful of a drug that he or she thinks is going to kill you. Let's look at the typical question asked the average Joe at Ala Moana Mall: "If you were terminally ill and in intractable pain, would you want the ability to end your own life early and thus avoid prolonged suffering and agony?" That's like offering a thirsty man a drink of water... of course the answer would be yes. The media asks that question because it is titillating… it postulates the absolutely worst possible situation and offers an easy out.

The *key* question the public should be asked by policy makers such as this body and by the media is, "How can we assure that when you are facing the end of your life, you will be cared for in a place and manner of your choosing, surrounded by those who love you and free from needless pain and suffering?"

As in most contentious public debates, the terms invoked in what is often called the death with dignity debate (DWD) are often ambiguously used and misused, a problem worsened by media sound bites.

Now, if I might suggest, let's talk about this debate without the loaded sound bites and misleading catch phrases.

Pro

Those who argue for PAS give priority to two basic claims:
1) the obligation to respect the autonomy of the dying, and
2) the obligation to relieve extreme pain and suffering. Other considerations, however, are also emphasized. These include the development of dehumanizing technology, the belief that "letting die" and "causing death" are virtually equivalent, and quality of life issues. Proponents often argue that modern commitments to self-determination, human dignity, and compassion require exceptions to traditional prohibitions against killing or suicide for compassionate reasons. It is important to point out that this past summer, the local proponents of the issue have stated that is no longer a matter of pain management, that it is more basically about autonomy.

Con

Those who oppose PAS, or various forms of euthanasia, argue on the priority of:
1) the meaning and role of suffering. They recognize the factors of contemporary culture that fuel interest in PAS, but do not believe these justify the rejection of long-standing and fundamental objections to suicide or killing. For example, they hold that the integrity of physician-patient relationships depends on a sole allegiance to care and healing that never takes life. They argue that there is a genuine distinction between "letting die" and "causing death." They believe practical considerations against PAS are insurmountable -- considerations such as the pressures it produces on the critically ill to justify remaining alive, abuse to the elderly and vulnerable (such as the disabled), and the difficulty of regulation, and
2) the communal nature of human life, and
3) God's purposes for life.

Given the basic understanding of the arguments, it is reasonable for the legislature to accord this issue considerable attention. You will hear opposing arguments that address the religious aspect, the "slippery slope," the lack of concurrent oversight in the Oregon system and the perspective that policy should not be based upon fear, rather upon the highest standards possible.

This morning, however, I want to offer you testimony that is very hopeful. It is based upon the awareness of a multitude of professionals who are professionally committed to improving the care of the dying.

I will start by reminding you of actions taken by this body since 1999 to improve end-of-life care. That was a big year:

- You passed the Uniform Health Care Decision Act (Modified) which gave Hawaii's people a state of the art Advance Directive. Since then, thousands of people have been taught about Advance Directives and Hawaii has one of the highest percentages of persons over 65 who have completed their advance directives.

- Also, a hospice reimbursement bill was passed, creating the first in the nation reimbursement mandate for hospice care from private insurances and the reimbursement of Hospice Residential Care.
- In 2000, you passed the legislation allowing persons to indicate the existence of advance directives on their driver's license. Again, this is another step to increasing the public's awareness of end-of-life issues.
- In 2001, you passed legislation removing significant regulatory barriers to pain management, by eliminating the need for duplicate prescriptions and allowing the physician to fax prescriptions for pain medicine (for the terminally ill) to the pharmacy, instead of causing the family to make multiple trips to the Doctor's office then the pharmacy.
- Finally, this year you are considering HB 1839, establishing a pain patient's bill of rights and your colleagues in the Senate are considering a bill instructing the Medical Board of Examiners to develop pain management guidelines.

It is important to remind you that the public policy leaders of Hawaii are making steady progress forward in the improvement of end-of-life care.

You are not alone!

Those of us in health care are as committed to the same mission as you have been. We are unceasing in our commitment to relieve pain and suffering and to offer as much choice as possible to terminally ill and their families. I want to tell you about a brand new 2-year grant to stimulate the development of our state's capacity to provide palliative care.

Project Overview
Kokua Mau will adopt a model to promote change agents within committed institutions on all islands. Teams of at least two healthcare professionals (physicians, registered nurses, social workers, chaplains) from each participating institution (hospitals, nursing homes, home care agencies, case management agencies, and other interested health care providers) will be trained in the principles of palliative care. In addition, professionals who work with the Aging Network (the Executive Office on Aging, the Area Agencies on Aging, and their contracted service providers) will continue to be trained and included.

Future Goals
This project's overarching goals are to:

- Expand access and improve quality of care at the end of life so that Hawaii's people may die in the place of their choosing, free of suffering, and treated according to their beliefs and values.
- Stimulate the development of the communities' capacity to provide palliative care services.
- Eliminate the terrible choice between curative and palliative care.
- Avoid costs related to inappropriate acute care at the end of life.

Anticipated outcomes from these interrelated programs will include:

- Integration of palliative care into existing healthcare systems.
- Development of community services to support dying patients and their families.

- Reductions in the inappropriate use of acute care.
- Increased use of hospice, and more timely referrals to hospice.
- Avoidance of the need to choose between palliative and curative treatment.
- High levels of measurable patient and family satisfaction with availability and benefits of palliative and hospice services.

Concurrent Activities

Currently, three other significant coordinated activities are underway to promote the whole community model:

- Kaiser Permanente Hawaii Region has initiated a two-year demonstration project in palliative care.
- HMSA ICMS has proposed a two-year pilot project on palliative care coordination to the Office of Personnel Management for the Federal Employees Health Benefits Program (FEHBP) Federal Plan 87.
- Representatives from major healthcare institutions throughout Hawaii have drafted a palliative care standards statement for use as a common foundation for healthcare agencies desiring to initiate palliative services.

All of this work, both from the legislature and from the health care community is having a positive impact. Since 1999 we have:

- More than 17,000 people have heard presentations about end of life issues, including advance directives and pain management.
- The Kokua Mau web site, with information about end of life care received more than 22,000 visits in the first year of operations.
- Numerous television, radio and print articles have been aired educating people about their options at the end of life.
- The completion rate of advance directives increased to 38% of the adults in the 45-64 year old group and to 68% in the 65+ group.
- As of December 2001, 11% of those renewing their driver's license indicated that that have an advance directive, with almost 5% of those with a state ID doing the same.
- Provided special training for the Aging Network and the Executive Office on Aging
- Develop a training manual for state agency on aging, provided more that 18 states.
- Trained more than 500 individuals from 33 faith based groups on "Care of the Dying" and "Care of the Bereaved"
- Developed a program to train caregivers in nursing home (the aides at the bedside) on issues related to "Care of the Dying" and "Care of the Bereaved"
- Implemented "Pain as the 5th vital sign" demonstration project with 12 nursing homes and two nursing colleges.
- Provided EPEC and ELNEC (specialized end of life training for doctors and nurses) training to health care professionals on several islands.
- Integrated training on end of life care in the JABSOM, including rotations for geriatric medical fellows. (Work continues on integrating end of life care into all aspects of medical training.)
- Authored more than 18 reports and scholarly publications.

- Prepared more than 14 brochures and booklets for public dissemination with more than 100,000 copies total
- Implemented a Palliative Care Demonstration project at Kaiser Hospitals
- Initiated the development of a pain and symptom management program at another respected hospital

Total money invested from 1999 to 2001, both cash and in-kind support was more than $2.25 million dollars.

- Hospice admissions have increased 20.2%
- Hospice average daily census has increased 34.9%
- Hospice average length of stay has increased 8.9%
- Seen a decline in the support of Physician assisted suicide (from 64% to 57% by year 2000 for age 45-64 and from 62% down to 46% for age 65+) According to Hawaii's Behavioral Risk Factor Surveillance System.
- Seen a decline in support of Voluntary Active Euthanasia.

I tell you all this because I want you to understand our level of commitment to providing good end of life care. It is critically important that we do not cease our efforts to improve End-of-Life Care in Hawaii.

You are called upon today to shape public policy. Yow will hear story after story oi someone dying in pain or an "undignified" death. These emotionally charged testimonies are designed to evoke that response from each of you. I urge you to look past these very heart-wrenching stories and look not at the individual, but at the entire community.

We are working hard to improve end of life care!

I urge you to consider the correct question, not one based upon fear.

"How can we assure that when you are facing the end of your life, you will be cared for in a place and manner of your choosing, surrounded by those who love you and free from needless pain and suffering?"

Public policy should be shaped by expectations of a greater good... a demand for increased access to hospice and palliative care. I urge you to hold this bill.

I can be reached at Hospice Hawaii 924-9255 for additional questions.