

EASING THE END OF LIFE JOURNEY

HELPING HANDS IN BRISTOL BAY

*"It is better for elders to be taken care of at home than to be sent away."
-Helping Hands Program*

People in rural areas in Alaska often have difficulty finding specialty medical services. Lack of human and financial resources mean that services available in urban areas need to be re-created in ways that work for sparsely populated areas. The Bristol Bay Area Health Corporation saw a need for hospice-like services to residents with chronic and terminal illnesses, but did not have the resources to adopt urban hospice programs. Instead, they designed a program that built on the strength of their community—caring people. The new program uses volunteers and existing medical resources in new ways.

In creating this new end of life care program, Bristol Bay Area Health Corporation tailored services and program materials to meet the cultural needs of area residents. Not only were materials developed in Yup'ik, with Yup'ik artwork, but the volunteer program itself strengthens Yup'ik culture by providing a place where elders can communicate their wisdom and life experiences to young people.

Alex's Story

By Helping Hands Program, BBAHC

Alex, a Yup'ik Eskimo, lived in the small village of Ekwok, Alaska, where he spent his life fishing, hunting, and raising his family. Now he was at the end of his life. Alex was bedridden and spoke very little. He was in Kakanak Hospital, and his wife, Anecia, had to fly to Dillingham to visit him. Once she knew Alex wasn't going to get better, Anecia decided that she wanted to take care of him at home near his family and friends. She didn't want him to stay in the hospital.

A hospital bed and other essentials were loaded into a small plane and flown to Ekwok. Personal Care Attendants (PCAs) that live in the village helped care for him. Weekly visits by a home health nurse, and regular phone calls supplemented his care. A physician visited Alex during scheduled village trips every few months. The primary treatment goal was to make him comfortable and pain-free.

At one point, Anecia grew tired of caring for Alex 24 hours a day. She wanted to go to a nearby village for a Russian Orthodox festival. Respite care was arranged. Alex would be flown to Dillingham's Kakanak Hospital for a few days. As soon as Anecia learned it was possible for her to have a break, it was all she needed—she decided she preferred to stay home with Alex.

Kristy, Alex's nurse, visited the household regularly. Rituals were established. She had a cup of tea with Anecia, and then examined Alex and changed his dressings. Then she left the room and came back with two jellybeans.

"Okay Alex, we've finished our work," Kristy said and gave Alex a jellybean and popped one in her mouth.

Ikavurtem Unatai



Helping Hands Program

Easing the end-of-life journey with care, comfort and choices

The logo—a mask with soft extended hands superimposing over a typical southwest Alaska scene—shows many things.

The Mask

Masks are a common part of Alaska Native culture.

Traditionally, shamans (medicine men) wore them during healing ceremonies, honoring the spirits.

The ceremonies were used to ask for guidance from the spirits.

Masks were also worn during celebrations to honor an animal, tell a story, or show a vision.

In this mask, one eye is open, one eye is closed—depicting the end of one journey and the beginning of another journey. Extended out from the mask are hands, the helper's hands, the heart of BBAHC's program.

The Background

Winding rivers are common throughout rural Alaska and meander through mountains and the tundra. They connect villages, and are a major pathways of travel. In addition, they carry salmon and other fish, an integral part of the Alaska Native lifestyle.

Alaska Native elders who know that death is near may talk about their "journey" and ask, "Who will cross the river with me?"

The Helping Hands Program will help the people complete their journey across the river.

Alex died at home on November 6, 1999. He was 86 years old. "I woke up at 6 AM and he seemed a little cool, so I put another blanket on him, and turned up the heat. At 8 am, I woke up again. It was very quiet. He wasn't breathing," his daughter Mollie said.

The men of the village built a simple wooden casket and painted it gray-blue. The whole village turned out for the funeral. It was a cold, clear day. When Kristy arrived, she went to the room in the school reserved for the family. She gave Anecia a hug.

"You took such good care of Alex," Kristy told her.

A Russian Orthodox funeral was held for Alex. After the service, each person viewed Alex and kissed him. Sons and brothers carried him to the gravesite. Alex's eleven-year-old grandson sang Amazing Grace, his young clear voice ringing out in the silent, cold winter air. As he sang, the men in Alex's family handed around a hammer. Each of them hammered a nail into the top of the casket. Ropes were placed around the casket and the men guided it into the ground. School was closed for the funeral, and afterwards, everyone met at the school to eat.

As part of the Helping Hands Program follow-up care, Kristy visited Anecia a few weeks later. "I'm doing okay," Anecia said. "I'm lonely, he had such a presence." "He died a good death," Kristy told her. "He died the way he wanted to—at home with no pain. He died gently."

In the following story, former and current employees of the Bristol Bay Area Health Corporation discuss the development of the Helping Hands Program.

Helping Hands: Easing the End of Life Journey*

By Christine A. DeCourtney, Kristina Jones & Nina Heavener

Only sixty years ago, Alaska Native elders died at home, surrounded by family and friends, in the small villages where they had lived most of their lives. Western health care shifted the location of dying from the familiarity and comfort of home to distant hospitals and nursing homes. Until recently, terminally ill elders in Bristol Bay often spent the last part of their lives in unfamiliar surroundings. Many died alone, without the emotional support of family and friends. Family and friends who live in the village were denied an opportunity to share in the elder's wisdom and knowledge and to participate in cultural practices surrounding end of life. Grief was compounded and complicated for survivors who had not been present for the death of a friend or relative.

As the numbers of elders increased in the Bristol Bay area, more area residents were being sent to Anchorage for health care that was focused on treatment and intensive care, rather than on comfort and symptom relief. One village resident kept her mother at home during her last year of life. She got little advice and help, as the hospital in Dillingham was not geared to provide this kind of care. A nurse employed by the Bristol Bay Area Health Corporation (BBAHC) saw the same need for appropriate end of life care. Together with another BBAHC employee, in 1994, they developed a

*Helping Hands: Establishing a Culturally Sensitive End of Life Care Program in Bristol Bay, Christine A. DeCourtney, Jones, Kristina, Heavener, Nina (submitted for publication)

program and sought funding. The proposal was approved, but not funded twice before it was funded by the Robert Wood Johnson Foundation.

The Helping Hands program supports the wish of the Native people of Bristol Bay. They want to be in a familiar setting, close to family and friends in their final days. Helping Hands helps patients and their families find comfort and care in those last days, within their own culture, among their friends and family, with familiar foods and Native medicines.

Program Design

Bristol Bay residents who have multiple chronic or a terminal illness are eligible for Helping Hands. The program design identifies a primary caregiver for each patient, trains village-based workers, and develops trained volunteers in each village. A home health nurse visits each patient on a regular basis and provides telephone support between visits. Patient care plans draw on basic village resources. The focus of the program is pain and symptom control, combined with training for family, health care providers and volunteers. The program was not designed to make a profit. It was developed with the belief that providing at-home care during the last part of life, and avoiding expensive medical evacuations and hospital stays, could reduce overall health care costs while improving quality of life and family experience.

The development of culturally sensitive program materials is an important part of the program's design. BBAHC had previously experienced a lack of success when trying to use mainstream program materials in a tobacco use cessation program. A literature review revealed little material that addressed end-of-life issues in American Indian/Alaska Native or in rural populations.

Focus groups with elders from the three Native cultures in Bristol Bay were held to aid in actual program design and materials development. Village tribal councils and village senior services were notified about meetings and their support requested. BBAHC staff and a medical anthropologist facilitated the focus groups. Focus group findings provided key information

that was incorporated into program materials and design. Some program materials were translated into Yup'ik and recorded on an audiocassette to help non-English speaking village elders understand the proposed program.

Elders provided valuable information and perspectives regarding needs and traditional practices around death. It was important for focus group facilitators to remain in the village overnight to provide opportunity for additional one-on-one sharing. Some of the most valuable information critical for successful program design was not revealed during the focus group but later in the day or evening. For instance, elders had difficulty understanding why their grandchildren, who had received training and worked as Personal Care Attendants (PCA), were "paid" to take care of them. Also, elders were ashamed when "outsiders" took care of them instead of family. This information was incorporated by BBAHC into a written story for villagers that discussed how times have changed in the village. The story uses the example of schools where paid teachers provide education as opposed to elders who were the only teachers many years ago.

Volunteers are important to Helping Hands. The volunteer program recruited village youth as well as adults. Approximately 10 villages have teen peer groups, called Peer Helpers. This prevention program, funded by the State of Alaska, is designed to help teens avoid substance abuse and suicide. The Peer Helpers receive training from the Helping Hands program volunteer coordinator in order to provide support to terminally ill elders. Teen volunteers help with chores and respite care. Another important function of the teen volunteers is the recording of traditional knowledge and experience into the journal each patient receives. This is especially important since many elders do not write, but are willing to share life experiences orally. In villages without Peer Helper programs, individual village youths are recruited as volunteers.

As program design progressed, it became evident that the Helping Hands program would never be able to meet existing state and federal

rules and regulations regarding hospices. One limitation was the requirement for nurses to be able to reach a patient within one hour, virtually impossible in most of the region. The initial concept of seeking Medicare certification was abandoned. Quality of life, pain and symptom control, reduction in costly medical evacuations and hospital stays, and the opportunity to involve family and friends in a traditionally important part of Native culture became the focus of the program.

Program Implementation

Implementation of the program took much longer than anticipated. Staff turnover added delays. The reality of living in remote communities, the need for constant and perilous travel on small planes, and the challenges of coordinating medical care with limited resources were problematic. Focus groups were cancelled and rescheduled due to weather and village cultural and religious observances.

Far more patients than anticipated became Helping Hands patients as the word spread about the program. Elders who had moved to Anchorage to get health care services for chronic and other medical problems moved back to their villages. Physicians at Anchorage and Dillingham hospitals allowed patients to go home because the Helping Hands Program could provide care for them at the end of life. Back in their home surroundings, many patients thrived and survived much longer than the prescribed “six months to death” medical pronouncement.

Unexpected problems surfaced. For example, the subsistence lifestyle that requires villagers to leave their homes in summer and travel to fish camps created problems of caring for infirm and frail elders left behind. Occasionally, patients returned to the village without the Helping Hands Program staff knowing about their return.

In response to what BBAHC learned, the Helping Hands Program was redesigned as part of the health corporation’s home health program to better address the longer than expected life of patients who returned to their home village. Care plans were developed around patient goals and the realities of a subsistence lifestyle.

For instance, berry picking was encouraged to promote healthy eating and exercise for patients with diabetes. Personal care attendants now visit more often when families are away fishing and hunting. Program staff work to make sure volunteers are available to provide meals and other needs when caregivers are involved in subsistence activities.

Program implementation called for extensive training of the region’s more than 80 Community Health Aides in care for comfort and symptom relief and in caring for elders nearing the end of life in the village. Family caregivers were eager for information that helped them understand what was happening to their loved one. The BBAHC home health nurse for the Helping Hands patients was able to respond to concerns by telephone and during village visits. As a result, emergency flights to Dillingham for physician visits declined for Helping Hands patients.

Since the program began in 1999, the percentage of home deaths for selected causes has changed from 33 percent in 1997 to 77 percent in 2001. The number of people dying at home with friends and family has more than doubled. Helping Hands has shown that end of life care can be combined with traditional customs in a cost effective and culturally responsive program. Elders in remote villages can remain at home, in familiar surroundings, as the end of life nears, and can pass along their wisdom and knowledge to the young people in the community.



Some Helping Hands Materials for Bristol Bay Residents

Mainstream American palliative care materials, particularly those designed for the general public, did not meet the needs of Alaska Native elders who could not relate to the depiction of home life, people and activities of daily living in the mainstream materials. A number of items were developed to aid in the understanding and acceptance of the *Helping Hands Program*:

- **Program brochure**, describes the program and how it integrates traditional ways and contemporary medicine.
- **Volunteer brochure**, explains why volunteers are important as someone nears the end of life and what the reader can do to help. It describes customary and traditional ways of helping such as bringing in firewood, smoking fish, and picking berries.
- ***Who Will Cross the River with Me? A storybook*** – As Native elders in Bristol Bay near the end of life, they often talk about crossing a river. The book incorporates findings from focus groups to describe a situation in which an elder is able to remain at home at the end of life. It incorporates a number of nuances of life in the village that are important to remember when an outsider comes into the village, e.g., always remove shoes at the door, sit down to have tea and talk, examine a patient in the presence of family and friends. The book is narrated in English and Yup'ik by a Yup'ik storyteller and linguist and available on an audiocassette. While there are three main Alaska Native groups in the Bristol Bay area, the predominate Native group is Yup'ik Eskimo which also has the largest number of non-English speaking elders.
- **Journal** – “When you are caring for someone who is dying, you don't have time to record his/her memories or stories or those of friends,” said a local nurse and a recent widow. The journal includes relevant prayers and poems, primarily Native American. There are sections for “Friends' Thoughts” with memory reminders, such as, “One of my favorite conversations with you ...” and “When I eat ___

I think of you ...” Another section is for the patient with headings such as, “What I want people to remember me most for is ...” and “What I will miss most is ...” The journals also include a place for a family tree. Since many of the elders were orphans (parents died during the Spanish Influenza epidemic) their families have a chance to gather history for younger generations. In one instance, a nurse took her husband along to visit a patient. The patient had grown up in the orphanage with the nurse's husband's father and was able to recount stories of his life as a young person.

Early results have shown that the journals are being used in a number of ways. Family and friends have filled some journals with memories. Others include elder stories recorded by visitors and teen volunteers. Some remain open in the Dillingham assisted living facility for people to write in as they wish. One of the early recipients was dubious of the value of the journal and skeptically paged through it. Suddenly he started telling a story of his youth and began smiling and laughing. It was the first time he had laughed in a long time.

The journals are very popular outside the program and have broader relevancy than anticipated. Proceeds from the sale of journals help in a small way to offset the costs of continuing the Helping Hands Program.

- **Caregiver, volunteer, CHA/P guides** – Loose-leaf notebooks provide information on how to care for patients nearing the end of life. While they contain many of the same materials mainstream guides include, traditional knowledge and wisdom sections are also included, as well as practical information that addresses caring for patients in a remote setting. The community health aide guide duplicates portions of the guide aides use to provide care as well as additional information. The caregiver guide includes a special first page “How to take care of ___.” The patient's name is written on the page as well as contact telephone numbers for nurses and the volunteer coordinator. A section on Native plants and medicines is also included in the guides.

WHAT NUMBERS CAN TELL US

Aging in Alaska

Alaska is first in the nation in the proportional growth of our senior population—with a 50 percent increase in people aged 65 years and older between 1990 and 1999. The number of Alaskans over 65 is expected to increase to over 90,000 by 2018, nearly triple the 2000 count. (*Alaska Population Overview: 1999 Estimates*, Alaska Department of Labor and Workforce Development).

Infectious diseases and injuries were major causes of death in 20th century Alaska. As life expectancy increased and the population aged, chronic diseases like cancer and heart disease have become the leading causes of death. More Alaskans will need care for these illnesses, and many will eventually be seeking end-of-life care in their own villages and communities. Rural areas will be challenged to provide services for their aging populations.

Programs like Helping Hands can measure success in terms of their goals. For example, Helping Hands gives results in meeting its goal of allowing more elders to be at home instead of in an institution at the end of life: “Since the program began in 1999, the percentage of home deaths for selected causes has changed from 33 percent in 1997 to 77 percent in 2001.”

THINGS TO CONSIDER

Is a program like Helping Hands something you need in your community?

Many Alaskans will need end of life care, care that provides comfort and pain relief during a terminal illness. Larger Alaskan communities have hospice programs funded through health insurance or Medicaid/Medicare. Hospices require specialists and other expensive resources not available in rural areas. Throughout rural Alaska, elders and others approaching the end of life have been sent to hospitals or nursing homes in urban areas for care, depriving them of familiar environments and the support of family and friends. Bristol Bay Area Health Corporation (BBAHC) recognized that home care in the village was more sensitive to

individual needs. When end of life care is provided in the village, the number of distressing and expensive medical evacuations by air can be reduced.

What are some of the challenges in setting up a program like Helping Hands?

Family members, health care providers, and volunteers must be trained in end of life care to create a program like Helping Hands. Many younger people in the community, and many members of the boarding school generations, had never cared for an elder dying at home before. Many health care providers had had little experience with end of life care.

Financing village-based end of life care programs is difficult. Such services are not reimbursed by insurers and Medicare. In order to assure funding for a nurse coordinator and a volunteer coordinator, Bristol Bay Area Health Corporation put Helping Hands in their Home Health Program, which is Medicare reimbursable. In general, funding agencies may not be flexible enough to pay for innovative programs. Efforts are needed to change Medicare/Medicaid regulations make end of life care reimbursable.

What are some of the strengths of the Helping Hands program?

BBAHC worked hard with residents to make sure the program met their needs in ways that supported their cultural values. From program design to challenges along the way, the residents’ needs and values were the top priority.

Development of the journal to record stories and memories provided a forum for elders to pass on traditional knowledge. The use of Peer Helpers not only provided volunteers but also linked generations, giving elders and youth the opportunities to spend time together.

Health care and social services were integrated and geared to the needs of regional residents. Providing care at home improves the quality of life for dying people. Often it adds good days to lives that would have been shorter in a hospital or nursing home.

TO FIND OUT MORE

For more information on caring for elders in the village and end-of-life care, see:
Promoting Excellence in End of Life Care
www.promotingexcellence.org/

American Association of Retired Persons (AARP)
End of Life Issues
www.aarp.org/endoflife/

Last Acts: A National Coalition to Improve Care and Caring
Near the End of Life
www.lastacts.org

Principles for care of patients at the end of life
Millbank Memorial Fund. December 1999
www.millbank.org/endoflife/

The May 2002 edition of the Indian Health Services Primary Health Care Provider is the Annual Elders Issue. It includes an article on Marrulut Eniit (Grandmother's House), a ten unit assisted living home in Dillingham. The issue also includes articles on arthritis and osteoporosis in American Indians and Alaska Natives, suggestions for discussing end-of-life planning and palliative care, and "Nine questions to ask yourself about elder care in your community". The Provider can be accessed online at www.ihs.gov/PublicInfo/Publications/HealthProvider/provider.asp.

The IHS Elder Care Initiative (www.ihs.gov/MedicalPrograms/Eldercare) sponsors a listserv to share information, resources, and ideas.

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REFERENCE CHAPTERS IN HEALTHY ALASKAN 2010, VOLUME I

Chapter 6. Education and Community-Based Programs
Chapter 15. Access to Quality Health Care
Chapter 20. Arthritis and Osteoporosis
Chapter 21. Heart Disease and Stroke
Chapter 22. Cancer
Chapter 23. Diabetes
Chapter 24. Respiratory Diseases
Chapter 25. Disability and Secondary Conditions
Chapter 26. Public Health Infrastructure

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