



Sharing Information & Giving Support to Hawai'i's Family Caregivers

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Caring From Afar Takes Many Forms

Long-distance caregiving takes many forms — from helping manage the money to arranging for in-home care; from providing respite care for a primary caregiver to helping a parent move to a new home or facility. What may start out as an occasional social phone call to share family news can eventually turn into regular phone calls about managing health insurance claims, getting medical information, and arranging for respite services. What begins as a monthly trip to check on Mom may turn into a larger project to move her to a nursing facility close to your home. If you are a long-distance caregiver, you are not alone.

So what do you do when you live on an island or continent away from your aging, ailing parents? There are no magic answers. You can hire someone to help --there's a cottage industry of companies that help long-distance family members --but you can't outsource it completely. Here are some tips for making a heart-wrenching, exhausting situation easier:

Appoint a sibling and a doctor.

Families should pick one sibling to be in charge of Mom and Dad's care, and to be in charge of communicating with doctors. Don't have multiple siblings calling the doctor. The appointed sibling should also have the parents' health care power of attorney. Similarly, appoint a doctor who's "captain of the ship." Older



adults tend to have lots of specialists, each prescribing medications that can interact with drugs another doctor has prescribed. Often, nobody is coordinating all their medications, and that's a significant problem. The appointed doctor ideally would be a geriatrician, but could be one of your parent's specialists.

Fly in for a visit with the appointed doctor. If you're the appointed child, go with your parent to one or more appointments with the "captain of the ship" doctor to establish a relationship. Do this at least once.

Find an E-mail-Friendly Doctor. Communicating with your parent's

doctor via e-mail is extremely valuable -- it's efficient, it's quick, and you don't end up leaving voice mail messages for each other. If you're shopping for a new doctor, specifically ask how they feel about communicating via e-mail; not all doctors are keen on it. Also, find a doctor who's willing to put your parent's medical records on the Internet. That way, you can see what happened at each doctor's visit. A number of websites offer services to upload medical records.

Establish a Network. Enlist the aid of your parents' friends and neighbors. Establish a telephone tree of people who at any time of day or night will be the first-response person.

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Upcoming & etc...

Family Caregiver Training Series May & June 2008

Kapiolani Community College (KCC) offers several series of workshops designed specifically for family caregivers interested in learning skills for the care of their elderly parents, spouse or relative. These workshops are planned by the KCC Kupuna Education Center and are taught by experienced health and elder care educators. This summer one of the series is being offered with more being planned for the Fall Semester.

The Basics of Family Caregiving

Family caregivers of an elder are provided an overview of caregiving during a series of six 2-hour workshops. Participants will learn what is involved in caring for a family elder; the skills that are needed for caregiving; and how to make decisions about providing care to a loved one. The workshops will include the following topics: assisting with activities of daily living such as dressing, bathing, and eating; normal aging and common chronic health conditions; managing medications; nutrition and diet; community services; legal and financial considerations; memory exercises to sharpen the aging mind; tips on caring for an elder with Alzheimer's or other dementias; and how to care for you, the caregiver. The skills learned in the 6 workshops are based on established techniques for ensuring safety, preserving dignity and preventing injury to both the elder and caregiver.

Instructor: Emelyn Kim, MS. Ms. Kim has a master's degree in Gerontological Counseling and is a National Certified Counselor. She has her own company called Elder Care Counseling and Education and is experienced in case management and elder care education. Pre-registration is required and class size is limited. For More Information on Kupuna Education Center programs, call Toni Hathaway at 734-9108 or visit www.kupunaeducation.com.

Caregiver's Conference: Caring for Family, Caring for Yourself

Saturday, November 1, 2008
8:00 am - 3:00 pm, Sheraton Waikiki
Registration (opens in June): \$45 for family caregivers; \$60 for profes-

sionals. Lunch and all sessions are included in registration fee.
Keynote speaker: Dr. Bill Thomas, AARP Visiting Scholar and Founder of the Eden Alternative.

There will be over 20 break-out sessions on topics related to eldercare. Participants may choose up to three. There will also be self-care activities, including massage, aromatherapy, and more! Finally, over 45 exhibitors who provide services to help family caregivers will be available at the Exhibitor Resource Fair. Save the date!

VA Caregiver Assistance Pilot Program: "E Malama Mau"

E Malama Mau (Enduring Care) is the VA – Pacific Islands Healthcare System's Caregiver Assistance Pilot Program. The program aims to provide overnight respite to eligible veterans living on the islands of Hawai'i, Kaua'i, Maui, and rural areas of O'ahu.

E Malama Mau is a partnership with veterans, their families, the community expanded adult residential care homes, and a VA interdisciplinary home-based primary care team situated on Hawai'i, Kaua'i, and Maui. As an alternative to institutionalization, E Malama Mau will offer overnight respite care to veterans in increments of either 15 days twice per calendar year, or 30 days once per calendar year.

"E Malama Mau" means continuous and/or enduring care. The VA- Pacific Islands Health Care System recognizes that family caregivers are the backbone of providing "enduring" care for many severely ill and disabled veterans. The emotional and physical demands of caregiving can eventually take its toll if not lessened by some form of assistance or respite.

For additional information and/or if interested in being an expanded care home with E Malama Mau, please contact Sara Tompkinson, LSW, of the VA Caregiver Assistance Pilot Program Coordinator at (808) 433-0224.

Telecaregiving Workshops Online

Expert advice is only a few clicks away! Family Caregiver Alliance (FCA) has added a new feature to its website, an online audio archive of TeleCaregiving Workshops. Originally presented over the phone to thousands

of caregivers and health professionals, the popular workshops offer caregivers the unique opportunity to learn practical care skills from expert instructors without leaving the comfort or convenience of their home or office.

Current workshop titles include:

- Caring Together! Sharing Caregiving Responsibilities with Siblings and other Family Members.
- How Do You Know If You Have a Memory Problem?
- Here but Not Here—Finding Hope. When Your Loved One Has Memory Loss.
- Keeping Away the Caregiver Blues.

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Family Caregiver
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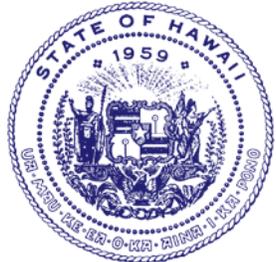
E LOA KE OLA

MAY LIFE BE LONG

The Executive Office on Aging is the state agency whose mission is to promote dignity and independence of older adults, and to help prepare for the rapid expansion of Hawai'i's aging population.

Phone: 808-586-0100
www4.hawaii.gov/eoa

Linda Lingle Governor	Michael Sumja Chair, Policy Advisory Board For Elder Affairs
Chiyome Leinaala Fukino, MD Director of Health	Wes Lum Caregiver Resource Initiative Project Coordinator
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Family Caregiver Awards Program

The Hawai'i Family Caregiver Coalition partnered with KHON2's Elderhood Project to launch the Family Caregiver Awards Program. The goal of this program is to improve the quality of life of family caregivers by recognizing and supporting the work of community agencies and other organizations that support family caregivers, as well as individuals involved with caregiving.

We are proud to announce the following award recipients:



Education Award: Alzheimer's Association, Hawai'i Chapter

The Alzheimer's Association's "Caregiver University for Family Caregivers: What Now?" program emphasizes strengthening the caregiver, while maximizing the abilities of persons with dementia rather than focusing on disabilities. The program is an orientation series of eight weekly sessions. Caregivers not only learn in greater detail about the disease and the impact and challenges on the family, but also learn skills such as:

- How to improve their ability to provide care, including medica-

tion management, appropriate nutrition, and personal care such as bathing and toileting.

- Identifying possible causes of behavior changes and how to manage difficult behaviors, and develop positive coping strategies.
- Identifying risk behaviors for wandering and the Safe Return program.

Support Award: St. Francis Hospice Bereavement Program

The St. Francis Hospice Bereavement Program provides psychosocial and emotional support for surviving caregivers during the first year following

the death of a loved one. Services consist of a multifaceted approach with the goal of facilitating the grieving process by offering a support system that includes:

- An annual memorial service, "A Rose for Remembrance."
- Bereavement volunteer support.
- Survivor's support group.
- Survivor's lunch bunch group.
- Annual St. Francis Hospice Family Potluck Picnic.
- Grief workshops.

Advocacy Award: Kokua Council

Kokua Council organized and convened a mock legislature, called the Silver Legislature – From Grumble to Rumble, to encourage and train older adults to advocate for senior issues. Supported by donations and grants, the Silver Legislature was implemented in 3 steps: (1) visiting senior organizations in 36 communities statewide to generate issues of concern; (2) Providing hands-on workshops in 8 areas statewide on how to lobby, write testimony, testify at hearings, and write letters to the editor; and (3) a two and a half day mock legislature at the Hawai'i State Capitol with seniors aged 60+ playing the roles of legislators, lobbyists, or observers. There were 150 attendees augmented by student volunteers and others providing staff support.

Caregiver Awards:

- Jay Feldman (Honolulu County).
- Ken Woo (Hawai'i County).
- May Tshako (Kaua'i County).

Caregiving From Afar

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Don't Expect Your Parents to Welcome Your Assistance. If you think your parents will welcome your help with open arms, think again. Most elderly people will resist your help, wanting to remain totally independent. And don't think that your parents will be willing to move to your city, even if you think that would make things easier on them (and you).

Logistical Advice. Finally, remember to have your parents' Social Security numbers, insurance policy numbers, and other financial information close at hand. Also, learn about the local services (such as Meals on Wheels, senior centers) available in your parents' hometown. It wouldn't hurt to also have your parents' local phone book on hand, too.

Upcoming & etc. . .

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- *Medications: Safe and Less Expensive Drug Therapy—A Caregiver's Role.*
- *There Must Be A Better Way Than This! Communicating with Someone with Dementia.*
- *Understanding and Treating Difficult Dementia Behaviors.*
- *Understanding Stroke and Vascular Dementia.*

Each title in the archive is available free, 24 hours a day, and includes an audiofile and companion written materials. Audiofiles are accessible in two formats: as an audio stream for instant online play, or as a file download for saving to a portable media device. The TeleCaregiving Audio Workshop Archives can be found on FCA's website at www.caregiver.org.

Dial 711 to Relay Your Message



Through Relay Hawai'i, the deaf, hard-of-hearing, and speech-disabled can communicate with friends, family, and coworkers through an array of traditional, online, or video relay services.

Simply dial 711 or the toll-free relay number to connect with a Relay Agent. The agent dials the requested number and relays the conversation between you and the other party. Calls can be made to anywhere in the world, 24 hours a day, 365 days a year with no restrictions on the number, length, or type of calls. This service is free for anyone to use. Free equipment is available upon request to eligible parties. This service is funded by a surcharge on all telephone bills.

TTY: This service is for deaf, hard-of-hearing, or speech-disabled users that wish to communicate with a hearing person. Dial 711 or 1-877-447-5990.

A deaf or hard-of-hearing caller uses a TTY to type his/her conversation to a communications agent, who then reads the typed conversation to a hearing person. The agent then relays the hearing person's spoken words by typing them back to the TTY user.

Captioned Telephone (CAPTEL):

This service is for individuals who are deaf and use their own voice, people

who wear hearing aids, or anyone with a hearing loss. When using a CAPTEL phone, the other party's spoken conversation is displayed word-for-word (almost simultaneously) in an easy-to-read window. After dialing, CAPTEL automatically connects to a captioning agent (behind the scenes) who transcribes everything the other party says into written text using state-of-the-art voice recognition systems.

Voice: Hearing people can easily initiate calls to any type of relay user by dialing 711 or 1-877-447-5991.

Speech-to-Speech: This service is for speech-disabled users calling friends, family, or businesses. Dial 711 or 1-877-447-8711. Specially trained local agents serve as the speech-disabled user's voice and repeat his/her responses to the other party.

Voice Carry-over: This service is for people with a hearing loss that prefer to speak. Dial 711 or 1-877-447-5992. Voice Carry-over (VCO) allows people with a hearing loss to speak directly to hearing people. When the hearing person speaks, the Relay agent serves as the VCO party's "ears" and types everything said to the TTY or VCO phone.

Hearing Carry-over (HCO): This

service is for people who can hear but have no audible or intelligible speech. Dial 711 or 1-877-447-5990. Using a text telephone (TTY), the HCO user types his/her conversation. A local agent then voices the typed words to the other party. When the other party replies, the HCO user listens directly to him/her.

Video Relay Service: This service is a communication solution for American Sign Language users.

Sprint IP Relay: A free service that combines relay service with the Internet, allowing users to make calls from any PC or selected web-enabled Internet wireless device without using traditional TTY equipment.

Sprint IP Wireless Relay: A service that allows customers who are deaf, hard-of-hearing, or who have a speech disability to use a wireless relay service on any wireless devices and any standard or mobile telephone user to make a relay call.

For more information about these free services or equipment, visit www.relayhawaii.com or email relayhawaii@sprint.com.





Caregiving and Aging Studies Reach Conclusions

Between May 2007 and January 2008, the Executive Office on Aging, and the University of Hawai'i's School of Social Work, Center on Aging, Public Policy Center, and the Department of Family and Consumer Sciences participated in eight research activities for the Joint Legislative Committee on Family Caregiving. Brief summaries of three of these studies are given below. If you would like electronic copies of any of these reports please contact the Executive Office on Aging at eoah@doh.hawaii.gov.

Family Caregiver Needs Assessment
Pacific Research and Planning Associates, the University of Hawai'i School of Social Work, the University of Hawai'i Center on Aging, December 2007.

This survey was undertaken to estimate the prevalence of unpaid caregiving in Hawai'i, to examine the characteristics of caregivers and

recipients, to determine what services were and were not used in caregiving, to estimate the costs of care and the impact, if any, of caregiving on employment, and to assess caregiver attitudes about public policies designed to assist them. The survey was done in the fall of 2007 using a probability sample of 600 caregiving households, obtained through random digit dialing. The sample was weighted to reflect 2006 Census estimates of the Hawai'i population. The study thus accurately reflects the characteristics and responses of family caregivers in Hawai'i.

Some major findings: (1) 26% of Hawai'i households have someone caring for a person over 60; (2) almost three quarters of these caregivers are women, whose average age is 54; (3) 27% of these households also have children under 18; (4) median household income is low (in the \$30,000-\$35,000 range); (5) over half (57%) of the care recipients

need help with personal care (*e.g.*, bathing, dressing, eating), and up to 85% need help with shopping, transportation, taking care of finances, and other activities; (6) caregivers provide, on average, over 20 hours/week of care, and 30% of the sample reported giving constant care; (7) less than 10% of caregivers use any paid help, either because they had all the help they needed, the cost of services, or the recipient not wanting services; (8) the most common unmet needs were better medical care and respite services; (9) in general, caregivers reported relatively low levels of stress; (10) 55% of caregivers were employed, and 27% of these said their work was affected by caregiving responsibilities; and (11) there was overwhelming support for state income tax credit for caregiving, and for a place to provide information and support.

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Caregiving and Aging Studies Reach Conclusions

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Older Adult Needs Assessment

Pacific Planning and Research Associates, University of Hawai'i School of Social Work, January 2008.

This report deals with part of a larger survey conducted in the fall of 2007 to determine the characteristics and needs of family caregivers, as well as older adults who have no caregivers. This part examines the characteristics and unmet needs of older adults who are without family caregivers. It describes their health problems, service use and non-use, and attitudes towards public policies designed to assist them. It is based on a probability sample of 210 households having an older

THE MOST COMMON CHRONIC HEALTH PROBLEMS WERE HEART DISEASE, HYPERTENSION, AND ARTHRITIS.

person with unmet needs, but no one acting as an informal caregiver. The sample was weighted to reflect 2006 Census estimates, and thus is representative of this segment of Hawai'i's older population.

Some major findings: (1) 66% of the sample was female, with a mean age of 73 years; (2) most were married, and 18% also had children under 18 living in the home; (3) median household income was about \$35,000 a year; (4) the most common chronic health problems were heart disease, hypertension, and arthritis; (5) half of the sample required help with bathing, dressing, eating, or other forms of personal care, and three quarters needed assistance with laundry, shopping, transportation, and other activities; (6) between 10 and 20% used some type of community service; (7)



the most common reasons for not using such services were cost (77%), not knowing where to go for help (69%), and long waiting lists (66%); (8) between 65% and 93% of these elders favored various forms of government assistance, the most popular of which was a state income tax credit for caregiving.

Eldercare Policies in the Workplace: Results of a Survey Conducted in 2007

Executive Office on Aging, December 2007.

The University of Hawai'i School of Social Work conducted this study through a contract with the Executive Office on Aging. The study was designed to determine the nature of eldercare policies in the Hawai'i workplace, and the availability of eldercare benefits; whether eldercare was seen as an employer issue; eldercare's effects on the workplace; and motivations for and obstacles to implementing eldercare benefits in Hawai'i's workplaces. The study used an online survey instrument, which was sent to a sample of businesses and non-profit organizations. Ultimately, 118 employers filled out the survey online.

Some major findings: (1) one third of employers indicated that at least 15% of their employees had their work affected by eldercare responsibilities; (2) the most common benefits offered were paid bereavement leave and unpaid family leave; (3)

almost 60% of employers felt that government should provide some eldercare benefits, with 70% favoring a tax credit for employers purchasing long term care insurance for their employees; (4) almost one-half favored a state subsidy to provide cash benefits or wage benefits for workers during an otherwise unpaid leave; (5) larger companies had more benefits, but smaller ones had more flexible practices; and (6) few companies collect any data on the costs or effects of eldercare policies.

Caregiver Services: Where Do I Start?

The best place to start in getting information on caregiver services in your community is your county office on aging. They can be reached at the following numbers:

Honolulu Elderly Affairs Division

768-7700

Kauai Agency on Elderly Affairs

241-4470

Maui County Office on Aging

270-7755

Hawai'i County Office on Aging

961-8600 (Hilo)

327-3597 (Kona)



Tutu's Corner

Latest Information for Grandparents raising Grandchildren

\$5,000 Grants for Grandparents Raising Grandchildren

The United Healthcare Children's Foundation announced the availability of new grants to help children who need critical health care treatment, services, or equipment that are not covered or not fully covered by their parents' health benefit plans. Grants of up to \$5,000 are available to help families pay for child health care services such as speech therapy, physical therapy, occupational therapy sessions, prescriptions, and medical equipment such as wheelchairs, orthotics and eyeglasses. Parents and legal guardians, including grandparents raising grandchildren, may apply for grants of up to \$5,000 for child medical



services and equipment by completing an online application available at the United Healthcare Children's Foundation website at www.uhccf.org.

Fact Sheets Focus on Relationships and Child Development

Grandparents who want to gain a better understanding of the grandchildren they care for will be interested in a series of nine fact sheets called "Through the Eyes of a Child: Grandparents Raising Grandchild-

dren." These fact sheets explore child development, relationships between grandparents and grandchildren, communication, child behaviors, and family patterns. Read the series by visiting www.uwex.edu/relationships.

Employers Cannot Discriminate Against Grandparent Caregivers

The Equal Employment Opportunity Commission (EEOC) said recently that employers cannot discriminate against grandparents and other caregivers because they are raising children. In a recent "Life at Work" column, which appeared in the Washington Post newspaper, writer Amy Joyce discussed the recent EEOC "guidance." A guidance is an official statement describing the EEOC's position on an issue. These statements are important because courts often refer to them when making decisions. A recent EEOC guidance makes it clear that existing laws that prohibit discrimination in the workplace apply to caregivers of all kinds. For example, says the EEOC, "an employer cannot deny a career opportunity to a worker because the employer thinks the workers' caregiving responsibilities will make him or her unreliable." The EEOC guidance gives specific examples of unlawful discrimination against adults caring for nieces, nephews, grandchildren, parents, and spouses.

Preventing Caregiver Exploitation

Older adults are living longer than ever. This longevity is unfortunately increasing the incidence of caregiver financial exploitation. Most cases involve family members or trusted associates and can include taking money or property, forging an older person's signature, and getting an older person to sign a deed or will through deception or coercion. We suggest managing your financial affairs through preventative steps such as:

- Using direct deposit for Social Security checks and retirement benefits.
- Keeping debit/credit cards, checkbooks and other valuables hidden

- if you have regular visitors to your home or apartment.
 - Reviewing your financial statements every month – especially if someone is paying your bills and managing your accounts.
 - Choosing your Power of Attorney with care and setting up a system of checks and balances so no one person has complete control.
 - Being careful about letting family, friends or tenants live in your house.
 - Treating home care workers like employees, not friends.
 - Maintaining contact with family, friends, and neighbors. The more
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Preventing Caregiver Exploitation

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active you are, the less likely you are to be exploited.

To avoid being a victim to home care workers who take advantage of older adults, we suggest conducting an attendant background check. Background checks include a review of job performance, verification that the information provided is accurate, and confirmation that the attendant can do the job requested.

- Ask for three references and call them all. At least two of the references should be from former employers.
- Talk with informal sources. Don't hesitate to contact the "friend of a friend" who originally suggested the person.
- Ask to see a photo identification card such as a valid driver's license or passport. Other valid forms of identification (ID) include: Department of Motor

Vehicles ID Card, Green Card, Military ID Card, Immigration Card, Alien Registration Card, or a valid out-of state Drivers License. Write down the number on the ID card. If the attendant will be providing transportation, get proof of a clean driving record by calling the DMV and verify license, insurance, and car dependability. Don't be afraid to ask for a test drive.

- If the person claims to be licensed, check with the licensing body, *e.g.* the Board of Nursing.
- Ask the attendant to sign (1) a waiver of confidentiality allowing you to view their personal history information, and (2) a waiver allowing you to run a credit check. If the prospective attendant is not willing to sign a form allowing the families to review personal records, the



attendant is probably not a suitable candidate for hire.

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