



# Family Caregiver

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

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## It's Time to End Caregiver Isolation

by Marilyn Seely, Long Term Care Planner

**H**idden behind thousands of doors, countless family dramas are being played out 24 hours around the clock, 7 days a week in every neighborhood in the state. This kind of day-to-day experience, the problems of caregivers, frustration and anger and reward may all be similar for thousands of people, but they are usually performed in isolation.

Isolation from the larger community, isolation from friends and even isolation from other family members.

Caregivers frequently ask themselves, "Why is this happening? What have we done to deserve this?"

Here we are in our 40s, 50s, 60s—and as author Anne Rice says in her description of aging, "we all wander as our health will allow—free, strong; dressing like the young if we want; sitting with feet propped up, casual; the first beneficiaries of an unprecedented health preserving often to the very end of life itself a faith in discovery." Then when we are just get-

*(Continued on page 2.)*

**For too long, caregivers have been silent, alone, isolated without a voice.**

## Easier Said Than Done

**J**eanette Nekota, a member of the Central O'ahu Caregivers' Support Group, earned her Master's Degree in Social Work from the University of Hawai'i, and a certificate from the institution's Center on Aging. For years, she has served as a social worker at a large local trust, dispensing advice and suggesting

relates Jeanette. A visit to Washington state revealed that her mother, Yoshiko, could no longer manage her own care and had lost the ability to verbalize. "She would pace back and forth, frequently fall, become disoriented or attempt to wander away from her home." Jeanette's husband and two school-aged daughters

agreed that Yoshiko needed to move to Hawai'i. Her father and brother remained in Seattle.

Jeanette continues her career, has resumed her neighborhood board chairperson duties and assists a dyslexic daughter's efforts to learn. Her husband, suffering from a work-related back injury, offers much support, but physical restrictions limit the amount of his assistance. Their home proved too small for five people, and needed to be expanded

and made accessible for a wheelchair. An adult day program needed to be found, records transferred, and numerous unexpected problems solved—all this while still providing long-distance care to her father. With no hospital-type respite available, work-required business trips have become a time of even higher stress, placing more demands on family members.

Yoshiko is no longer able to walk. Her upright appearance belies her total unresponsiveness and need for

*(Continued on page 2.)*



*Jeanette Nekota and her mother Yoshiko.*

resources to caregivers and others seeking assistance. Previously, clients' blank stares and skeptical looks held little relevance to her. But in 1998, when Jeanette sought help for herself and her mother from the same list of resources, she discovered that "it was easier said than done." The waiting lists, the cost, program limitations, and services that often didn't fit her needs surprised and frustrated her.

"In 1997, my brother called from Seattle to say that my parents had been involved in a car accident,"

## It's Time to End Caregiver Isolation

*(Continued from page 1.)*

ting comfortable with our lives and perhaps our newfound freedom, we become responsible for the health and welfare—even the survival—of a parent or spouse or sibling or a child whose health is failing.

For too long, caregivers have been silent, alone, isolated without a voice. What we need now is a chorus of caregivers' voices telling your stories and defining how the resources in such a program could help you with your caregiving efforts. Now is the time to join together and sing out so that everyone hears.

Caregiver Jody Mishan so wonderfully described caregivers in her poem:

*We are moonbeams.*

*The caregivers who support each other.*

*We are the circle of wounded spirits*

*That come together to sing our hearts out.*

Now is the time for all caregivers in Hawai'i to sing their hearts out so that everyone can hear, and will no longer ignore this hidden problem. Please join this "Caregiver's Chorus,"

See the article, "Caregivers, Let Your Voices be Heard," on this page for details.

## Easier Said Than Done

*(Continued from page 1.)*

complete assistance. "If anyone asks, I say that I'm fine, because nobody understands unless they have been a caregiver," Jeanette explains. "I fully understand now. I didn't before. For me, being a caregiver requires constant juggling and re-juggling of schedules, never catching up with all that needs to be done, struggling to find appropriate assistance, living with fatigue, and so much more. But we want to keep my mother at home with us as long as possible, do the best we can to keep her happy and comfortable. We just try to do the best we can."

## Caregivers, Let Your Voices be Heard!

**F**amily caregivers have been silent long enough. Join a "Caregiver's Chorus." Let your voice be heard by telling us your story in your own words. The Executive Office on Aging is gathering and compiling as many stories as possible from family caregivers on their caregiving experiences. This information will be critical in helping to advocate on behalf of family caregivers and their loved ones.

How? Because stories give statistics new meaning. While statistics are needed, they do not capture the human aspects of caregiving like stories do. Stories are a powerful and moving tool which connects people.

Even though you may think your story is not interesting enough, everyone has a unique story to tell and we want to hear from you. We want to hear about your caregiving experience—the trials, worries, costs, joys and the rewards.

What do you feel and think about your role as a family caregiver and

how have you grown or changed from the experience? It is our hope that by writing your story, it will not only provide you a public voice, but will also be an outlet for your feelings and concerns, and may possibly provide answers to others who are struggling along this journey.

Stories may be of any length. Let us know if we may use your story and name publicly, or if you prefer that we keep it anonymous. Also, let us know if we may share your story with interested parties (e.g. the legislature, newsletter articles in this publication, media, private and government agencies).


We know your stories will be recognized, valued and appreciated by those who read them. We regret that we are not able to send back any stories or pictures that are submitted. Stories may be submitted to:

**The Executive Office on Aging  
Attn: Family Caregivers' Project  
250 S. Hotel St., Suite 406  
Honolulu, HI 96813.**


## In Memory of Charles T. Kawano

**I**t is with great sadness that we inform you of the passing of Mr. Charles T. Kawano, who, along with his caregivers, was featured in the last issue of **Family Caregiver** under "Karen's Story: A Caregivers Journey."

Mr. Kawano passed away on November 8, 2002. He was 93 years old and is survived by his two daughters, a son and three grandsons. Mr. Kawano was lovingly cared for by his daughters Karen Koles and Carolene Neely, and grandsons Jason and David Neely for over 10 years. They approached the difficult and rewarding task of caregiving as a family with unending courage, compassion, and humor. Our sincerest condolences go out to Mr. Kawano's family, and especially his wonderful caregivers. We wish for them all that brings them comfort during this difficult time.



The Executive Office on Aging is the state agency whose mission is to assure the well-being of Hawai'i's 200,000+ adults age 60 and over.

 **Linda Lingle**  
Governor

**Wayne Hikida**  
Chair, Policy Advisory Board for Elder Affairs

**Gwen Ouye-Nakama**  
Caregiver Resource Initiative Project Coordinator

E LOA KE OLA  
MAY LIFE BE LONG

**Phone: 808-586-0100**  
**www.hawaii.gov/health/eoa**

# Alternative Medicines: What You Should Know

by *Randolf Oba, PharmD*

The subject of alternative medications is both a sensitive and controversial topic. Alternative medicines may also be called complementary medicines if they can help in conjunction with regular therapy. Often, people will receive recommendations from well-intentioned friends or relatives touting the virtues of some wonderful cure or symptom reliever. One must approach these items with caution. Many of these “medications” fall under the category of food supplements which are not regulated by the Food and Drug Administration (FDA).



entific studies that prove their efficacy. It is called evidence-based medicine. The problem with many of these alternative therapies is that there is no hard scientific data to prove their efficacy or safety. The physician, as well as the pharmacist, may have no idea about potential drug interactions with some of these



Care should be exercised in considering the source, quality, purity, safety and effectiveness. Use of these items should be discussed with your physician. The physician has your best interest at heart, and should be willing to provide you with an adequate explanation on the advisability of taking a particular preparation. However, be advised that not all preparations are properly labeled with regard to ingredients and strength. At the same time, everyone's medical condition, allergy profile and immune condition differs. Something that works for one person may not work for another. In some cases, information about some of these medicines is very sketchy or prone to rumors, and the truth of their efficacy cannot or has not been proven.

Modern medicine is based on sci-

entific data to prove their efficacy or safety. The physician, as well as the pharmacist, may have no idea about potential drug interactions with some of these items simply because they have not been studied. Just because something is “natural” doesn't make it good. Both hemlock and oleander are natural, and both are poisonous. This is not to say that there may not be some very good remedies out there.

We are constantly being bombarded with information about miracle cures

and revolutionary claims. Be cautious. Your health and your life may depend on it. Unfortunately, the peo-

ple most often victimized by false or unfounded claims are the chronically or terminally ill. Question these claims and ask for references. Armed with these references, you can consult your physician for advice. The problem with many remedies, programs or cures is that you are asked to embark on a very expensive regimen. Is the person selling you the products a professional? Again, buyer beware. You are the ultimate decision-maker. Likewise, question your health care practitioner when you have questions about traditional



medical therapies. It should go both ways. You should understand the therapies that you are undergoing. Full explanations should be expected. Don't blindly accept any therapy. Ask about potential side effects, adverse reactions, the cost of therapy, insurance coverage and the length of treatment. Educate yourself and ask your doctor and pharmacist questions.

## Upcoming & etc...

### Caregiving TV documentaries available on video

If you missed it on TV, “And Thou Shalt Honor...Caring for Our Aging Parents, Spouses and Friends” and “Caregiving in Hawai'i” are available on video. Call the Executive Office on Aging at 586-0100 for details on borrowing a copy of these programs.

### Do you have something to share?

If you have an interesting story, helpful tip, easy and healthy recipe, poem, etc. to share, we would like to

hear from you. Send your information to us:

The Executive Office on Aging  
Caregivers Resource Initiative Project  
250 S. Hotel St., Suite 406  
Honolulu, HI 96813  
E-mail: [eoamail.health.state.hi.us](mailto:eoamail.health.state.hi.us)

*(Due to volume, we can't print all submitted materials and will not be able to return photos or written materials. The Executive Office on Aging reserves the right to print what is deemed appropriate for the newsletter.)*

**Look for the next issue of Family Caregiver, scheduled to be released in Spring 2003.**

# Bill to Support Caregivers to be Introduced

**A** bill is being introduced in both the House and Senate to support family caregivers of seniors in Hawai'i. The bill is titled, "Relating to Family Caregivers," and would provide needed money to the Executive Office on Aging for the establishment of an advisory board on family caregiving

issues; the establishment of a family caregiver coordinator position; the development of training for family caregivers; and respite for family caregivers.

Representative Marilyn Lee is taking the lead for the introduction of this bill in

the House, while Senators Roz Baker and Suzanne Chun Oakland are taking the lead in the Senate. To get a copy of the bill, you may visit the website at [www.capitol.hawaii.gov](http://www.capitol.hawaii.gov). You may also call your legislative representative and ask them to send you a copy, or you may pick up a copy from the capitol print shop located at the State Capitol, 415 South Beretania Street.

Your voice does count. If you would like to provide comment or support on this bill or others, get involved in the legislative process. You don't need to be politically savvy or need a lot of time in order to participate and be heard. The best thing to do is to contact your legislative representatives in both the House and the Senate. Remember, they work for you, their constituent.

If your legislative representative is not the chairperson or a committee member of the committees that the measure has been assigned to, you may want to call the committee

chairperson and members to express your opinion about the measure. This is important because the committee chairperson and members will decide whether or not the measure will proceed.

While a written statement or testimony about the measure is best, a phone call or an e-mail is better than nothing. Be as concise as possible, especially in your opening statement. For example, in the beginning of your letter, e-mail or phone call, state whether you support or oppose the measure. Then provide the reason(s) why you feel the way you do and how the measure would help or hurt your situation.

If you would like help in composing a statement, or if you need general help with the legislative process, the Public Access Room at the State Capitol is an excellent resource for the public. Located in Room 401, the room has equipment and materials that you may use, such as computer terminals, typewriters, telephones, copies of legislative documents, reference materials, a fax machine and a copy machine. Available by phone or in person, staff is available to assist you with questions you may have. You can reach the Public Access Room by calling 587-0478. All Public Access Room services are free of charge.

**The best thing to do is to contact your legislative representatives in both the House and the Senate. Remember, they work for you, their constituent.**

## Featured Caregiver Support Group

**Central O'ahu Support Group**  
Contact: Lani Nedbal ek  
Leave Message at: 621-2288

**I**n 1997, State Representative Marilyn Lee asked a friend, "Do you think we should start a caregivers' support group?" That question, a "Yes" response from her caregiving friend and a newspaper article led to a small group of strangers gathering in a Wahiawa General Hospital classroom. The first meeting in October 1997 set the agenda for future meetings of learning and sharing. One woman cared for her 100-year-old mother; two others cared for husbands with Parkinson's Disease. The mother of another had Alzheimer's disease and several others cared for parents with strokes and dementia. All were family caregivers.

The group meets every second Thursday of the month (except in

December) from 7:00 to 9:00 pm. "Every month, we have wonderful speakers who generously share their knowledge and time with us," explained Marilyn, the group's president. "We have learned so much from all of them." Monthly newsletters summarize the guest speaker's presentation and announces upcoming events and other items of interest. A web site ([www.wvpress.com/care](http://www.wvpress.com/care)) duplicates the information for wider distribution and also includes a section on resources and literature offered in the group's small library (located at 823 Olive Avenue).

An hour of caregiver sharing follows the presentation. It is a time when members can express their feelings without hesitation, knowing that everyone understands. Members include former care-

givers whose loved ones have passed on. They serve as valuable assets by offering support to those continuing to provide care. Anyone interested in the group may leave a message at 621-2288 for Lani Nedbalek.

**It is a time when members can express their feelings without hesitation, knowing that everyone understands.**

# REACHing Out to Stop Elder Abuse

by Selina Lau

The Executive Office on Aging is pleased to announce the official launch of Project REACH: a state initiative to respond to the problem of elder abuse and neglect. Since August 2002, Project REACH began to provide support and counseling to older adults who are at risk of abuse; have been physically, psychologically or sexually abused; financially exploited; and/or neglected by others or by one's self. Services are available to individuals who are 60 years of age or older, and live in their own home or with family.

Services are without charge and include:

- **Information & Referral.**

- **Case Management.**
- **Financial Counseling and Management.**
- **Supportive Counseling.**
- **Legal Counseling and Services.**

Elder abuse and neglect are serious problems which are increasing. It reaches across all economic and social groups and strikes at the heart of families. For years, it was thought to be a "family issue" and taboos existed that kept people from talking about it outside of their own families. Once the issues of elder abuse and neglect were studied, the truth began to emerge. Older people, much like children, are most vulnerable when they are unable to take care of themselves. Many frail, older adults in our communities are hid-

den from public view, isolated in their homes and sometimes endure situations ranging from psychological abuse to financial exploitation to physical and sexual abuse. Project REACH was designed to bring these issues to the forefront, where the community can understand what is going on and begin to take action in putting a stop to it. REACH also offers a modest beginning to developing a system to give needy elderly persons and their families support, training and counseling to break the cycle of abuse and neglect.

For referral or services, please call the Honolulu Gerontology Program of Child & Family Service at 543-8468. For more information, please call Selina Lau at the Executive Office On Aging at 586-0100.

## Join the Hawaii Family Caregivers Network

The State of Hawai'i's Executive Office on Aging and its partners are developing the Hawai'i Family Caregivers Network to enhance family (informal and unpaid) caregiver support efforts.

### What is the Network for?

- To provide a coordinated means to get information out to family caregivers on a number of issues such as services, caregiving tips, legislation and training opportunities.
- To provide a coordinated means for family caregivers to comment or respond to family caregiving needs and issues.
- To gain information on the diversity and complexity of family caregiving issues in Hawai'i. Network members may serve as a vital source of information to researchers on caregiving problems and issues specific to Hawai'i. (Research participation of network members would be strictly voluntary.)

### What are the benefits of joining?

- To get information on national, state and local caregiving issues.

- To comment on and provide information on family caregiving issues.
- To receive **free** newsletters on family caregiving issues.

### Who should join?

- Any family (informal and unpaid) caregiver to a senior (60 years & older) family member, friend or neighbor.
- A grandparent who is 60 years

and older caring for a dependent grandchild.

If you are interested in joining, please complete the enrollment form below and mail it to: The Executive Office on Aging at 250 S. Hotel St., Suite 406, Honolulu, HI 96813; or fax it to (808) 586-0185. Please call (808) 586-0100 if you have any questions.

*We will not share any coalition member's personal information with other organizations.*

### Membership Sign-Up • Hawaii Family Caregivers Network

Caregiver's Name: \_\_\_\_\_ Phone No. \_\_\_\_\_

Mailing Address: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_ Age: \_\_\_\_\_ Male/Female: \_\_\_\_\_

Who are you caring for (e.g. mother, uncle, neighbor, etc.): \_\_\_\_\_

How long have you been the caregiver? \_\_\_\_\_ Are you the only caregiver? \_\_\_\_\_

How many hours (approximate) of care per month do you provide? \_\_\_\_\_

# Help for Family Caregivers

To help family caregivers, the City and County of Honolulu, Elderly Affairs Division (EAD), Department of Community Service, focuses on identifying and promoting awareness of caregiver needs and advocates on their behalf. Family caregivers who live on O'ahu can contact the Information and Assistance Senior Hotline at 523-4545 for help. Community Service Aides make home visits and conduct island-wide outreach to link people to resources. Monthly education/support groups are held to enhance caregiving skills and ease the challenges caregivers face. Call 523-4762 for information on these sessions.

EAD also contracts for services with the following agencies to provide services to assist caregivers:

- **Alzheimer's Association - Aloha Chapter (591-2771)** will be implementing a program to train caregivers on the special nutritional needs of Alzheimer's patients.
- **Franciscan Adult Day Care's "C.A.R.E. Club" (988-5678)** will offer caregiver support and education.
- **Ohana Care, Honolulu Gerontology Program, Child and Family Service (543-8468)** provides counseling, case management and supplemental services.
- **Kokua Kalihi Valley Elderly Program (848-0977)** now offers two caregiver support groups (one in Ilocano) and subsidies for respite care.

## 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  
**523-4545**

Kaua'i Agency on Elderly Affairs  
**241-6400**

Maui County Office on Aging  
**270-7755**

Hawai'i County Office on Aging  
**961-8600 (Hilo)**  
**327-3597 (Kona)**

- **Project Dana's "Caring for the Caregiver" (945-3736)** nurtures caregivers through counseling, education, and recreational and therapeutic activities.

## Caregivers Gather on Maui for Conference

On July 22, 2002, caregivers gathered on Maui for the first time during a conference held to discuss and learn from their issues and concerns. Caregivers are a growing group in Maui County.

The conference was called "Caring for the Caregiver: A Caregiver's Support Conference." It was co-sponsored by the Maui County Office On Aging, AARP-Hawai'i, HMSA and Kalama Heights Retirement Community.

The conference featured a host of wonderful speakers, including Elinor Ginzler, Manager of AARP's National Long Term Care and Independent Living Programs, who spoke about the hard work of being a caregiver and the importance of caring for yourself. Other speakers included Dr. Joseph Pepping from Kaiser Permanente, a married couple that provides caregiving and a panel of representatives from the Legal Aid Society of Hawai'i, Maui Adult Day Care, Hospice Maui, the Department of Health - Public Health Nursing Branch and the Alzheimer's Association - Aloha Chapter.

The conference was a beginning effort to address the struggles of caregiving and to form support and capacity/skill-building networks for caregivers. "Caring for the Caregiver," will be an annual event.

Through the National Family Caregivers Support Program of the Older Americans Act, the Maui County

Office On Aging is planning to expand its services to all caregivers with initiatives and partnerships in counseling and support groups, educational and skill-building classes and with the establishment of a Caregiver Resource Center. The Center will also be the conduit for on-line and Internet services for caregivers. For more information, call the Maui County Office On Aging at 270-7755 or 270-7774.

## Tuna Tofu Patties

**Number of servings: 4**

### Ingredients:

- 1 (20 oz.) container tofu
- 2 stalks green onion
- 1 (6 oz.) can tuna in water
- 1 egg
- Salt and pepper to taste
- Oil

### Directions:

1. WRAP tofu in a clean dishcloth and squeeze out water.
2. In a medium bowl, MASH tofu.
3. CHOP green onions to 1/2 inch lengths.
4. DRAIN tuna

5. ADD tuna, egg, onion, salt, pepper to tofu mixture. MIX well.
6. FORM into patties.
7. In large frying pan, ADD oil and FRY patties until brown.
8. DRAIN on paper towel and serve with any sauce.

### Variations:

May use salmon instead of tuna.

Dept. of Human Nutrition, Food and Animal Services, College of Tropical Agriculture and Human Resources, University of Hawai'i at Manoa. Information taken from the Food Skills Cookbook at [www2.hawaii.edu/foodskills/resources.htm](http://www2.hawaii.edu/foodskills/resources.htm).

# Core Exercises for Caregivers

by Bruce Hosaka

**A**s caregivers, your health and well being is important not only for you but also the loved ones you are taking care of. If you are sick or hurt, your ability to take

As caregivers, your health and well being is important not only for you but also the loved ones you are taking care of.

care of others and do the things you enjoy is limited. One of the more popular topics recently in the health and fitness industry is core training. The following is a discussion of core training and how it can help you.

Core training involves conditioning the deep abdominal and back muscles of the trunk and the hip and leg muscles. These muscles are the core, or foundation, of functional human performance, from the simple movement of lifting a box, to complex movement in sports. Core training also involves conditioning the neuro-muscular system to improve balance and stability.

The primary benefits of core training are:

- Improving your ability and performance for everyday activities and sports.
- Reducing the risk of injury and falls, and speeding your recovery if you do get hurt.
- Helping you to look and feel better and stronger.

The following are some basic core training exercises you can include in your daily fitness program:

## 1. Drawing In

Lie on your back with your knees

bent. Draw or pull in your belly button towards the floor (towards your spine) using your deep stomach muscles. Your hips and back should not move while drawing in, just your belly button. Imagine yourself pulling your belly button in while putting on a tight pair of pants. Hold for 3 seconds and do 10 repetitions. Repeat in a sitting and standing position.

## 2. Good Posture

Sit in the middle of a chair; your back should not be touching the back of the chair and your feet



should be flat on the ground. Sit “tall” like someone is pulling you up from your head, “draw in” your belly button, and hold this position for 1 minute. Gradually work up to 5 minutes straight. You can also do this while watching TV or reading.

## 3. Chair Squats

Sit with “good posture” on the edge of a chair, feet slightly wider than shoulder width apart, flat on

the ground and close to the chair. Look straight ahead, “draw in” your belly button, then stand up using your leg muscles. Slowly lower yourself back down to the chair, reaching back with your hips while continuing to look straight ahead. If you have trouble doing the exercise, you can use your arms to assist you. Start with 3 to 5 repetitions and gradually work up to 10 repetitions.

## 4. Arm Swings

Stand with your feet shoulder width apart. “Draw in” your belly button and swing your arms overhead and down for 10 repetitions. Repeat for 10 repetitions while swinging your arms across and back, crossing in front of your body.

## 5. Balance

Stand with good posture. Balance on one leg with your arms to your side. Hold for 5 seconds and do 3 repetitions for each side. Gradually work up to 30 seconds. For safety, stand between the backs of two chairs (see photo left) for assistance if needed.

Consult with your physician if you have an injury, have a history of cardiovascular problems or are just starting an

exercise program. If you feel pain or become lightheaded, stop the exercise. Remember to breathe while exercising. Do not hold your breath. Include cardiovascular exercises such as walking in your exercise program—your heart is a muscle too!

Finally, exercise is only one part of a health and fitness program. Good nutrition, stress management and spiritual health complete a well rounded program.

# Pearl

*Layer by layer my identity imperceptibly falls away  
Until one day I wake up  
And no longer know what I want,  
Who I am.  
I pad myself with more food, more weight  
To feel nurtured at least.  
I shove responsibilities to myself and others  
Under the rug.  
An old familiar voice inside me says,  
"I want to be free."  
But the new voice says,  
"Later. Right now you must care for Dad."  
You are now in a monastery  
Devoted to a Higher Cause.  
You are now getting a PhD in Alzheimer's Caregiving.  
Which voice do I listen to?  
Which one is the right one?  
I shove the conflict under the rug too  
Just to get through the day.  
The days that I get through  
Have turned into months, a year..*

*I try and find myself from time to time,  
With differing levels of passion.  
I give up, then try again.  
I nourish my spirit when I can,  
And find the strength to go on.  
But I want out.  
I want to be free of the prison.  
I want to graduate.  
But then a spontaneous exchange of love  
Warms my heart and soul,  
Showing me again  
That this prison sentence is a gateway  
To understanding compassion.  
And compassion is stronger than fear or anger.  
I am thankful again.  
Grace wins. Love works.  
So I go on. And on. And on.*

—**Jody Mishan** ©2001

*Source:*  
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