



## Caring for a person with Alzheimer's disease

©National Institute on Aging

Finding out that a loved one has Alzheimer's disease can be overwhelming, stressful and frightening. According to the National Institute on Aging, here are some tips that may help: Ask the doctor any questions you may have about Alzheimer's. Find out what treatment might work best to alleviate symptoms or address behavior problems. Contact organizations such as the Alzheimer's Disease Education and Referral Center (ADEAR) for more information about the disease, treatment options and caregiving resources. You can call ADEAR at 800-438-4380 or visit the website at [www.alzheimers.org](http://www.alzheimers.org). Study your day to see if you can develop a routine that makes things go more smoothly. If there are times of the day that a person is less confused and more cooperative, plan your routine to make the most of these moments. Keep in mind that the way a person functions may change from day to day, so try to be flexible and adapt your routine as needed. Consider using adult daycare or respite services to ease the day-to-day demands of caregiving. These services allow you to have a break while knowing that the person with Alzheimer's is being well cared for. Begin to plan for the future. This may include getting financial and legal documents in order, investigating long-term options and determining what services are covered by health insurance and Medicare.

### Frequently asked questions—

*How can a caregiver create a safe home environment for someone with Alzheimer's?*

Research shows that the physical environment in which the person with Alzheimer's disease lives can be important in stimulating cognitive functioning, promoting independence, improving safety, managing behaviors, and reducing stress and anxiety. Creating a safe living environment can be important in preventing many stressful and dangerous situations. If the person begins to wander, consider installing secure locks on all outside windows and doors and removing locks on bathroom doors to prevent the person from locking him or herself in. Medications should be labeled and locked up. Knives, matches, lighters, and guns should be secured and out of reach. Keep the house free of clutter and remove scatter rugs and anything else that might contribute to a fall. Childproof latches on kitchen cabinets or any place where chemicals or cleaning supplies are kept.

*What kind of behaviors does a person with Alzheimer's exhibit?*

Alzheimer's is a progressive disease—the symptoms grow worse over time. Yet, it is a variable disease. Symptoms progress at different rates and in different patterns. The appearance and progression of symptoms will vary from one person to the next. The behaviors a

person exhibits will be based on how advanced the disease is and the particular way he or she is affected. Symptoms will likely include confusion, memory loss, and problems with routine tasks. The person may also experience anxiety, sleep disturbances, and difficulty recognizing family and friends, among a variety of other symptoms. Sometimes the person with Alzheimer's disease may exhibit violent behaviors, wandering, restlessness, and/or inappropriate social or sexual behavior. Not all people experience all of these problems, and the intensity and duration of these behaviors may vary. Most of these behaviors, if they occur, happen in the middle stages of the disease, and can often be helped with medication or behavioral interventions.

*How should a caregiver handle bathing a person with Alzheimer's?*



The caregiver should draw the person's bath and should adjust the water temperature to avoid scalding. The room should be warm

and free of scattered rugs, and the bathtub should have a nonskid covering. A hand-held showerhead on a flexible cable can help with washing, and a shower or tub bench with grab bars can prevent slipping. Also, make sure that there are enough towels to quickly dry the person, preserve their dignity, and keep warm.

*What steps should a caregiver take when the person with Alzheimer's becomes incontinent?*

It is important to have a routine for taking the person to the bathroom and to stick to it closely as possible. A good rule of thumb is to plan to take the person to the bathroom every 2-3 hours during the day. Don't wait for the person to ask.

*When is the right time to contact hospice for a person who has Alzheimer's disease?*

When a person with Alzheimer's disease starts to decline, such as a decrease in appetite, weight loss, frequent hospitalizations, frequent pneumonia, urinary tract infections, etc., you might want to consider placing them on hospice. Hospice provides additional support for the caregiver. With the many services that hospice provides such as a 24 hour on-call nurse, symptom management and respite care, they also have the ability to provide a social worker to assist with the financial burden involved by providing legal and community resources. Hospice aides help provide assistance in the activities of daily living, chaplain for spiritual support along with volunteers to provide special care that may benefit your loved one.

## Better Living Festival

On Saturday, August 19, 2006 there will be a Better Living Festival held at the Mid-America Center, One Arena Way, Council Bluffs, Iowa 51501 from 9:00 am to 3:00 pm. There will be no cost for this event.

At the Festival there will be over 75 vendor booths dealing with subjects such as Healthcare, Investment and Finance, Leisure, In-Home Care, Residential Facilities, Information and Supportive Services, Pharmaceuticals, Pharmacies, Hospitals, Hospice, Community Resources, Relaxation, Hobbies and much more.

There will be activities for the whole family like face-painting, clowns, musical entertainment all day long, massage therapy, reflexology, food booths, health screenings and balloon animals to name a few.

There will be Informational Presentations on informative subjects such as Elder Abuse, Family Caregiving, Home modification for healthy aging, etc. People who would benefit attending the Better Living Festival would be Seniors, Family Caregivers, Baby Boomers and those who will be retiring in the next 10 years



along with individuals who want to be proactive in determining what kind of retirement they will have.

Hospice with Heart will also have a booth. We are promoting the theme "It's How You Live".

Learn about options for end-of-life services and care; Implement plans to ensure wishes are honored; Voice decisions to family, friends and health care providers;

Engage in personal or community efforts to improve end-of-life care.

Please take some time and visit our booth along with all the other booths that will be there. We are told that the Mid-America Center is hosting a Rib Fest in the parking lot the same day so that should be fun.

## Hospice with Heart Memorial Service

The memorial service that was held on May 7th was a great success. A great number of families and friends attended. Our chaplain did a great job with the service as there were a lot of compliments. Letters of Hope were read by our staff and volunteers. These letters were written by a family member of four individual patients. Each letter described a different outlook on the grief process.

The memorial quilt turned out wonderful. The family members who participated in making quilt squares were pleased with the outcome. We currently have it displayed in our office, feel free to stop by and see it.

Mayor Tom Hanafan joined our service acknowledging those people who help provide care for hospice patients such as physicians, nursing home facilities, health care professionals, volunteers and staff. To end the service everyone gathered outside for the releasing of butterflies. This represented that the loved ones that

*"In memory of those  
cared for in 2005"*



had passed have all gone to a better place, each headed a different direction free of pain and sickness.

## Chaplain's Corner by Frank Fast

"Cry like you mean it."

You can choose to cry again...if it helps you to move on and accept the changes in your life without regrets. Grief is one of the most difficult things in life to overcome. When someone dies, you mourn not only the loss of the loved one, but also the loss of a stage of life that can never be recaptured.

Though the variety of circumstances are rich among the people we meet, there is one common threat—life means change. We must be encouraged to embrace our grief and allow others around us to grieve as well. Sometimes as we attempt to cut our grief

short, we end up hurting ourselves as well as cheating those around us.

We need that last walk with a sister, that final memory-maker with a co-worker, that walk through the house so full of memories we will leave behind.

So, we then find that we need to cry. We may have cried over a puppy once or a friendship lost...maybe even a toy left behind. And we will cry again, even over silly things—if it means we can move on and accept the changes in our lives with no regrets.

## Love and Chicken Soup by Synthia L. Cathcart, RN

---



A comedian once told his mother that he had only a short time to live. Upon hearing the distressing news his mother said, "Sit Down, I'll make you some chicken soup." The man asked, "Do you really think that will help me now?" His

mother responded with a hopeful smile, "It couldn't hurt."

Many caregivers for terminally ill patients feel the same way. Because food is symbolic of love and nurturing, it is extremely difficult for family members to see their loved one have no desire or be unable to eat. A common reaction is to want to begin using nutritional supplements, tube feeding, or even use I.V. nutrition with the idea that "It couldn't hurt." Published facts now indicate that the use of forced nutrition in terminally ill persons is now of questionable benefit and may actually worsen a patient's condition.

Findings recently published in several studies point out that intravenous nutrition or forced feedings can lead to several harmful effects in the terminally ill.

1. The rate of tumor growth may increase. Feedings may provide more nourishment for the tumor than the patient which will actually shorten the life expectancy.
2. Forced feeding with oral supplements or tube feedings can increase the patient's G.I. distress causing them increased suffering.
3. Serious infections are often an occurrence associated with the use of I.V. nutrition (TPN).
4. True weight gain with these methods is marginal. The gain is usually attributed to fluid retention.

When a caregiver sees the family member eating less and less or

eating nothing at all, it is often the first time they face the realization that their loved one will die soon. If they can keep the patient eating, "They will live longer, right?" It is difficult for loving family members to understand that by pressuring or forcing a patient to eat, their death won't be put off and their suffering may be increased.

This does not mean that there is nothing that can be done when the appetite begins to decrease. It is helpful to have small, frequent meals. If any supplements are added, the homemade variety is best tolerated. Puddings, gravies, soups, and milkshakes can be made with whole milk fortified with powdered milk. Hard candy helps to moisten a dry mouth and add calories at the same time. Medications to control nausea and vomiting may be helpful in allowing the patient who desires to eat to do so comfortably as possible.

However, in spite of all the interventions, there will come a time in most terminal illnesses when a patient no longer feels any desire to eat and in fact may be repulsed by food. When this occurs, no matter how upsetting to the family, the patients should not be pressured or forced into eating. The caregiver needs to be reassured that their loved one is not trying to commit suicide or becoming so depressed that they won't eat. This is part of the terminal process. Allowing the patient not to eat is in no way negligent, rather it is in the best interest of the patient. At this time, the family may need more constant reassurance than the patient.

The issue of nutrition is probably one of the most guilt inducing, frustrating and emotionally charged issues that terminally ill patients and their families ever deal with but with proper teaching and emotional support both the family and the patient can make informed decisions based on what is best for the patient, allowing the patient to live and die as comfortably as possible. What is best sometimes means HOLD THE CHICKEN SOUP and substitute LOVE.

## Our Capital Campaign Begins

---

As you know, one of our goals is to build the first Hospice House in Council Bluffs. We have started our Capital Campaign by going out into the community to ask for support.

Currently patients requiring hospice house services would have to travel to Des Moines to reach the closest Iowa facility. The proposed 12-room facility will include many amenities of "home" for patients and their families. We are beginning our campaign to raise the \$3.74 million dollars needed for this house.

Based on the Center for Disease Control's 2004 morbidity and mortality figures, approximately 1,900 people could have utilized hospice services in southwest Iowa. These figures are based on all terminal diagnosis by county and include potential patients from Fremont, Harrison, Mills, Pottawattamie, Cass, Montgom-

ery, Page and Shelby counties. In 2005, Hospice with Heart's initial year of operation, provided services to 70 patients. Of the 70 served, 18 could have utilized a hospice house facility due to equipment needs, uncontrollable symptoms and level of comfort during the end-of-life process. An additional 7 patients could have utilized the hospice house to have symptoms controlled and be released back to their homes. The hospice house will offer a new level of service to the residents of southwest Iowa during a time when patients and their families face the stress of life-limiting terminal illness, often times with no place to go.

A donation to the Hospice with Heart House will ensure that people with a terminal illness will have a choice on how to spend their last days.



**QUARTERLY NEWSLETTER**

300 West Broadway  
Suite 114  
Council Bluffs, IA 51503  
Phone: 712-325-6802  
Fax: 712-322-2671  
Email: [hospice@hospicewithheart.org](mailto:hospice@hospicewithheart.org)

***Where Quality Care Comes From  
The Heart***

**We're on the Web  
[hospicewithheart.org](http://hospicewithheart.org)**

## Hospice with Heart Donation Form

**Donor Information**

Name: \_\_\_\_\_

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

City/State/Zip: \_\_\_\_\_

Amount of Gift \_\_\_\_\_

I want my gift to go towards:

- General Fund       Hospice House

My gift is in memory of: \_\_\_\_\_

**We would like to thank you for your gift that allows us to continue to provide quality care to those who need it.**