Long Term Care and Family Grief

When home care for a loved one with dementia has reached its limits, many families consider nursing home care. They may rely on the recommendation of the physician or it may be a crisis situation such as an accident or critical medical problem that takes the matter out of their hands. It could just be that the health problems and care needs exceed family caregiving capabilities. Regardless of how and when the decision is made, the choice for nursing home placement evokes strong emotions of grief and sadness in family members.

Grief is not just a reaction to death. It is a reaction to loss—any loss. There can be a sense that when persons with dementia move into care settings they are being abandoned by their families. Control over their care and routines are lost to those of nursing facilities. Families often experience feelings of guilt and sadness when they can no longer personally care for their loved ones.

Long term care is a choice based on benefits for both persons with dementia and their family caregivers. Looking at those benefits can help families move away from the feelings of failure.

Persons with dementia living in care facilities receive care from persons with expertise in aging and dementia. Long term care facilities offer special programs and activities tailored to the abilities and interests of persons with Alzheimer’s disease. Health problems can be identified and treated early. Structural routines in long term care mean a predictable, manageable reality for those with dementia.

Family caregivers are relieved of the daily physical care routines and medical and scientific relations. “The fact that there are no effective treatments for Alzheimer’s has allowed the disease to pass diabetes. It is vitally important that we increase Alzheimer’s research funding to slow or stop the progression of this devastating disease.”

Alzheimer’s is Now Sixth-Leading Cause of Death

Alzheimer’s disease is now the sixth-leading cause of death in the United States, surpassing diabetes, according to the Centers for Disease Control and Prevention (CDC).

The CDC estimates that 72,914 Americans died of Alzheimer’s disease in 2006. Today, as many as 5.2 million Americans are living with Alzheimer’s disease.

“The CDC’s announcement that Alzheimer’s disease jumped from the seventh to the sixth-leading cause of death should serve as a wake-up call to the nation,” said William Thies, Ph.D., Alzheimer’s Association vice president of medical and scientific relations. “The fact that there are no effective treatments for Alzheimer’s has allowed the disease to pass diabetes. It is vitally important that we increase Alzheimer’s research funding to slow or stop the progression of this devastating disease.”

Grief...continued on page ten

Cause of Death... continued on page six
Dear Friends and Supporters,

Almost daily, the media report new research findings about Alzheimer’s disease. When coupled with information available on the internet, we are inundated with information. Because of your connection to the Alzheimer’s Association, it’s likely that you follow these stories closely. While many reports sound promising and give reason for hope, there can also be a certain amount of confusion, if not contradiction, in the news about Alzheimer’s research.

The Alzheimer’s Association, as the leading non-profit supporter of Alzheimer research, wants the public to understand the significance of research findings and be able to interpret information appropriately. The following are some tips to help you determine the validity of research and help you react appropriately to research findings:

What kind of research was conducted? Basic research is test tube and microscope research that is designed to build a basic level of understanding about cells, compounds, biological processes, etc. Basic research is the beginning of the long process of discovery for understanding the progression of Alzheimer’s, finding clues to prevention, improving treatment, and ultimately curing the disease. Promising reports about findings of basic research do not mean a cure for Alzheimer’s is just around the corner, but rather that an important step has been taken. For example, a story that reports a new compound improves brain functioning in mice should not be interpreted to mean that the compound will improve brain functioning in humans, let alone reverse Alzheimer’s.

Another type of research is clinical research, which is the testing of compounds or potential new drugs on humans. A lengthy serious of clinical trials must be completed before new treatments for are approved for human use. News reports about findings of clinical trials are less frequent because of the length and cost of clinical trials. Positive news on clinical trials, especially those with a large number of subjects, provides the most hope in the arena of Alzheimer’s research.

Sipfle...continued on page three
Caregiver Playbook Available

There are an estimated 5.2 million Americans living with Alzheimer’s disease, and almost 10 million Americans caring for a person with Alzheimer’s or another dementia.

To raise awareness of the many resources available to caregivers of those living with Alzheimer’s, Coach Frank Broyles, athletic director of the Arkansas Razorbacks, has teamed with the Alzheimer’s Association on “Playbook for Alzheimer’s Caregivers.”

The Playbook is a football-themed, practical guide Coach created after caring for his wife, Barbara, who had Alzheimer’s. The playbook, as well as other caregiver tools, is available at no charge from the Alzheimer’s Association by calling 1.800.272.3900.

Pieces of my Heart Jewelry Available

Pieces of My Heart is unique jewelry, made exclusively for the Alzheimer’s Association, Greater Iowa Chapter by local artist Gretchen Stanislav, and available for a limited time. Pins and necklaces are available for $10 each. For more information or to order, contact the chapter at 515-440-2722 or email lisa.stephany@alz.org.

A puzzle piece represents Alzheimer’s disease as it progresses, robbing people of their memories, lives and families. Finally, one is left with only a few pieces, far too few, to put together a complete life.

The heart is the love we have for our affected friends and loved ones. It represents the hope that we will be able to help them.

All proceeds from the sale of the jewelry will support our mission to eliminate Alzheimer’s disease through the advancement of research, provide support for all affected by Alzheimer’s disease, and to promote brain health.

How many “subjects” were involved in the research study? Subjects are the people used to test a treatment, medication or process in a research study. Research findings on a study with one or a few subjects should not be generalized to the entire population. The more subjects used, the more reliable the results.

Have the study results been replicated by other researchers? If several researchers obtain the same or similar results, it is likely the findings are valid. Findings of significant research projects are published in scientific journals, which require peer review. These journals help to spread the news of the results to other researchers, who can learn from their counterparts across the world, incorporate findings into other studies or use ideas to develop new research projects.

With an increasing concern about Alzheimer’s and the acceleration of new findings from research, we want our friends and supporters to be wise consumers of information. As always, please visit us at www.alz.org to learn the latest about Alzheimer research.

Sincerely,

Carol L. Siple
Nominate Your Pharmacist and Help the Greater Iowa Chapter

You only have until Sept. 30, 2008, to nominate your pharmacist for the C.A.R.E™ (Commitment to Alzheimer’s Recognition of Excellence) Pharmacy Award. The award recognizes the pharmacist’s critical role in supporting people with Alzheimer’s disease and their families.

We invite you to recognize a pharmacist who has taken a leadership role in our community.

If the pharmacist you nominate is named the winner, the Greater Iowa Chapter will receive a $1,500 donation. Our chapter will receive another $1,500 donation if the most nominations are received from our area. These donations will help support resources we provide to people with dementia and their caregivers living in our community.

To be eligible, the pharmacist must:

♦ Be licensed. Pharmacy technicians or assistants are not eligible.
♦ Be involved in activities that have a positive effect on people with Alzheimer’s disease and their families.
♦ Have been involved in these activities some time during the last year.

For a nomination form and more information, visit www.carepharmacyaward.com.
There are so many great reasons to participate in Memory Walk, from raising critically needed funds to spreading awareness and honoring a loved one.

Below, two walkers tell their reasons.

“The Memory Walk is very important to me and my team because my Grandmother had Alzheimer’s. We watched this dreadful disease slowly take her from us. When someone has Alzheimer’s not only do they suffer but all your family and friends suffer as well.

We walk, as a family, in honor of Grandma and others like her, and because it’s very important to us to help find a cure to end the suffering.”
Kristie Stapp

“I lost my mom to Alzheimer’s in March, 2008. She had not spoken to me, nor did I have any interaction with her for over 3 years, but she still remained in some ways my mother. I encourage all of you to walk in your nearest Memory Walk. Celebrate the lives of those we have lost and those who are still fighting. I believe that within our lifetime there will be some kind of cure and walks will no longer be needed. But until that day we need you to help us fight for those who can’t.”

Nancy Rudnick

Team Stapp at the 2007 Memory Walk

(left to right)
Mary Decker & Nancy Rudnick

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Go to www.alz.org/greateriowa to be linked to your Memory Walk website. Register, fundraise and help spread the word!
Research Update

Ginkgo Biloba Findings
Ginkgo biloba, an herbal extract commonly marketed as a memory aid, is not an effective treatment for dementia, according to a recent study.

A six-month trial of 176 people in London with mild-to-moderate dementia found no difference between those taking ginkgo biloba and those given a placebo. Researchers measured participants’ cognitive skills and quality of life at two, four and six months. Tests included exercises such as recalling words from memory and answering questions about time or places.

There was no evidence that the standard dose of ginkgo biloba, used by an estimated 10 percent of people with dementia, had any benefit on memory. Quality of life, as reported by the person with dementia or their caregiver, also did not improve.

Familial Risk Factors
Children face an increased risk of Alzheimer’s if both parents have the disease, a recent study reports. The study found that 42 percent of children whose parents both had Alzheimer’s went on to develop the disease by age 70. The risk is also greater for developing the disease early if additional relatives had Alzheimer’s disease.

School of Medicine in Seattle, said, “The exact magnitude of the risk, we don’t know yet.” Researchers collected data on grown children in 111 families where both parents had Alzheimer’s. Out of 297 children, 23 percent developed the disease. That compares to 6 to 13 percent of people in the general population who would be expected to develop the disease.

If other family members also develop Alzheimer’s disease, the children in the study were more likely to develop the disease earlier. For example, if only the parents developed Alzheimer’s, the typical age of onset among the children was 72. However, if one parent had family members with the disease, the age of onset in their offspring dropped to 60. If both parents had a family history of Alzheimer’s, the age of onset was 57.

Cause of Death... continued from page one

With the disease poised to strike 10 million boomers, this escalating epidemic must be addressed now. We need your help:

♦ Become a Champion for the Alzheimer cause.

♦ Write Congress today and ask your legislators to increase federal Alzheimer research funding and support crucial clinical trials.

♦ Donate to our vision of a world without Alzheimer’s disease.

Learn how you can help us fight Alzheimer’s disease by visiting www.actionalz.org/ or by calling the Alzheimer’s Association at 1.800.272.3900.

For the latest information on breaking Alzheimer’s news, research and care information, go to www.alz.org.

Information on the programs and services offered by the Alzheimer’s Association, Greater Iowa Chapter, can be found at www.alz.org/greateriowa.
Memorials, Honorariums and General Donations received 3-31-08 to 6-30-08

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<td>Ken &amp; Nancy Anderson, Steve &amp; Tammy Dmohoski, Courtland &amp; Kim Holman</td>
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<td>W.E. Page, Jr.</td>
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<td>PAUL BAER</td>
<td>Anna M. Riepe</td>
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<td>Clifford &amp; Marilee Hicks</td>
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<td>Frank Wright</td>
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<td>JACOB LEE</td>
<td>Bob &amp; Barbara Finch, Adrian &amp; Annette Hull, Travis &amp; Peggi Knight, Thomas &amp; Linda Sharpnack</td>
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Memorials, honorariums and donations listed are $25 and above. Every attempt is made to ensure correct information, but if there is an error, please contact the Alzheimer’s Association at 515.440.2722.
Memorials, Honorariums and General Donations received 3-31-08 to 6-30-08

EDNAM LEVINGS
National Veterinary Services Laboratories

HAROLD C. LOUNSBERRY
Ruth Lounsberry

ROBERT LUTZ
Dawn Lutz

PHYLLIS MARKWARD
S. Bomme
David & Linda Markward

ROBERT MCCARTEN
Patricia Berry

JOHN MILLER
Michael & Adonica Gould

GEORGE MONTY
Edward & Jennifer Bick

HALEAN O’KLOCK
Lonna Andolshek
Arvid & Karen Herstedt
David & Susan Herstedt
Helen Kushlakus
Edward & Mildred Macik
Wayne & Roxanne Nash
Max O’Klock
Mikel & Ann O’Klock
Barbara Pokrajac
Earl & Janice Swanson
Comprehensive Psychological Services, LLP

HAROLD OTT
Edwin & N. Gail Estes
Roger & Linda Goostree
Bobbie Holloway
Maxine Johnsen
Wayne & Barbara McDougal
Kevin & Diane O’Hara
Elaine Ott
Wells Fargo Bank, N.A.

MARTIN PARDEKOOPER, JR.
Phyllis E. Pearson

GRACE PARNELL
Lenon & Darlys Sifrit

GEORGE PEEL
Lawrence Ball
Geoffrey & Julie Cowan
Tim & Mary Scurlong
Curwood Extrusion Area Employees

CLEMENTINE PETERSON
Sarah H. Fletcher
Leo & Veronica Kearns
Patricia Kemp

Henry Krueger
Lonnie & Judy Swift
Janice Wear Winfield

DOROTHY POST
Donald & June Engstrom

DALLAS PURDY
Wanda Purdy

DIANE RED
John & Elizabeth Neumann

ROBERT K. REISTE
Steve & LaDonna Bosma
Evelyn Reiste

JACK ROACH
Jack Roach Estate

WILLIAM SCHOCKENMOEL
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STANLEY SYMONAITIS
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Karen A. Ficek

CAROLYN TIMMONS
Terry Warren

LYNN WELKER
Roger & Carol Volker
Chris Volder
Mary Years

VIRGINIA WALLACE
Tom & Cindy Fischer

ROSELLA WEBB
George & Patti Kirts

GRACE WILSON
N. L. & A. P. Brooks
Mary Dalmasso
Raymond L. & Cyndi Hummer
John & Sara Matlak
Louis & Marietta Peterson
Bethel Vincent

FRANK WOOLEVER
Richard & Rosemary Hutchinson
Beverly Robinson

General Donations

Charitable Gifts

Many of us enjoy making gifts to further causes in which we believe. But, of necessity, our own economic security must come first. For that reason, you may consider a charitable gift to the Alzheimer’s Association from assets that remain after you have assured your own economic security and that of your loved ones.

This charitable gift to the Alzheimer’s Association can be accomplished in a number of ways—through a bequest in your will, a remainder interest in a revocable living trust, a beneficiary designation of life insurance or retirement plan proceeds, or one of a number of other convenient vehicles.

An organized approach to estate planning can bring order to what may otherwise seem to be an overwhelming task. As a place to begin, focus your planning on four elements: the people in your life, the property you own, your plans for the future, and the planners who will assist you in achieving your goals.

People: List the individual for whom you bear financial responsibility. Include your spouse, children and parents. Many choose to include their charitable interests as well.

Property: Make a list of all property you own or expect to own in the future. Include real estate, stocks, bonds, mutual funds, the current value of life insurance policies and expected proceeds, retirement plan balances, and personal property. Beside each item, place a conser-
to this decision but there are interventions that can ease the grief process for family caregivers. If you need help with long term care decisions, contact the Alzheimer’s Association at 1.800.272.3900.

**Chapter Families Participate in Research Study on Caregiver’s Grief**

A study that examines caregiver grief reaction is being conducted by the University of Iowa School of Social Work. Dr. Sara Saunders has invited caregivers who are actively participating in a caregiving role complete a survey about factors that can contribute to feelings of grief. For more information, please contact the Alzheimer’s Association at 515.440.2722.

**24-Hour Helpline**

1.800.272.3900

Grief...continued from page one

can focus on meeting the psychological and emotional needs of their loved ones living in long term care. They are reassured that the care needs and medical support of their loved ones are in the hands of trained professionals. Families have time to meet their own needs and can associate with other families traveling similar ground.

Forming a partnership with care center staff is key to assisting families with the grief associated with long term care placement. This partnership starts by staying involved in the care of loved ones. Participating in care conferences and helping care center staff to really know loved ones through life story books are two ways to secure the important role that families still have in caring for their loved ones. When families are still involved it helps to lessen the sadness associated with placing loved ones in long term care.

If families made promises to loved ones that they would not place them in long term care; that was the right thing at that time. Care situations continually change and the difficult but loving decision may mean sharing the care through long term care placement. Feelings of loss and grief are normal reactions to this decision but there are interventions that can ease the grief process for family caregivers. If you need help with long term care decisions, contact the Alzheimer’s Association at 1.800.272.3900.

**Plans:** Think about what you wish to accomplish financially over the remainder of your life. Do you anticipate having adequate income to support yourself and your dependents? Who would you like to receive your property when you no longer need it? Would you like for heirs to receive property, an income, or both? Have recent tax law changes affected your plans?

**Planners:** To make sure your estate plan performs as you intend, you may need the assistance of your attorney, accountant, and/or other professional advisors.

We hope that you’ll consider joining the thoughtful and generous donors who have made an important impact on Alzheimer’s research and programs and services for all affected by the disease through a gift from their estate. But the vehicle you choose through which to make your gift is as important and personal as your estate plans. Your professional planned can help you decide which vehicle is best suited to your needs.

The Alzheimer’s Association, Greater Iowa Chapter has information on the variety of ways to include a charitable gift in your estate plans. For more information, please contact Lisa Stephany at 515.440.2722 or lisa.stephany@alz.org.
Join celebrities as an Alzheimer’s Champion

As many as 5.2 million people in the United States have Alzheimer’s disease, and by 2050, there will be almost a million new cases a year — unless we do something about it now.

That’s why celebrities from the worlds of entertainment and sports, including Penny Marshall, Garry Marshall, Ronny Marshall, Molly Sims, Wayne Brady, Leeza Gibbons, Terrell Owens, Bryant Gumbel, Anthony Anderson and Kathy Mattea have lent their faces and voices to help the Alzheimer’s Association challenge 5 million Americans – one for every person with the disease – to learn about Alzheimer’s and become an Alzheimer’s Champion.

The celebrity Champions are highlighted in a series of compelling photographs that will be exhibited across the country. In addition, national television, print and radio advertising aims to dispel public misperceptions and move people to take action in the fight against Alzheimer’s in the following ways:

**ACT** now to end Alzheimer’s – learn about the disease and get involved in the fight.

**VOICE** your support – become an advocate, help spread the word about the disease and tell your story.

**MOVE** the Alzheimer’s Association’s cause forward – join a Memory Walk or volunteer at a local chapter.

**OPEN** your mind – learn the facts about Alzheimer’s and donate to the Association.

Learn more about how you can become a Champion by visiting www.alz.org.

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**Newsletter and Information Options**

The Alzheimer’s Association, Greater Iowa Chapter, will be offering email updates to caregivers, family members and advocates on the latest disease, political and caregiving information. Readers also have the option of receiving the newsletter via email, rather than a printed copy through the mail. This saves the chapter crucial funds on printing and mailing costs, and electronic subscribers receive the newsletter and updates faster.

If you would like to sign up for the e-newsletter and any e-updates for family caregivers, professionals or advocates, please email Gale.Brubaker@alz.org and specify which updates you would prefer.
**Dubuque Golf Tournament a Success**

The 3rd Annual Johnny Orr UnFOREgettable Golf Classic was held at Thunder Hills Country Club in Peosta, IA, June 16, 2008, with 79 golfers attending.

The golfers, including former Iowa State University basketball coach Johnny Orr, enjoyed lunch provided by Lynch BBQ, team photos taken by Cliff Stock Photography and a shotgun start at 1pm. Most golfers completed their 18 holes by 5:30pm, followed with a delicious dinner provided by Thunder Hills Country Club. The emcee for the evening was the always-entertaining Gary Dolfin, and auctioneer Dennie Meyer and son Luke Meyer provided some auctioneering fun.

The evening came to a close with the presentation of a pen and ink drawing to Coach Orr of himself and wife Romie. The print was drawn by Dolores Chadwell, a well known artist from Anamosa, and framing was donated by Creative Touch Gallery of Dubuque.

The 3rd Annual Johnny Orr UnFOREgettable Golf Classic raised over $11,000. Thanks to all the sponsors and golfers who made this event a success.