**Announcements:**

June is Iowa Caregivers Month:
You still have time to honor direct care workers. Check the ICA Website to learn how you can honor direct care workers. You’ll find the 2008 proclamation language, a press release and much more. You can now also submit your “Touched by a Caregiver” Story on the ICA website. Go to www.iowacaregivers.org to find out more.

September 8 and 9, 2008
• Iowa CareGivers Association Annual Conference
  “Recipes for Care...Well Done” (Look for the brochure/scholarship application soon)

Remember to visit our website for announcements, program information, and resources.
www.iowacaregivers.org

Alzheimer’s Association-Greater Iowa Chapter will be holding their fall conference on October 16, 2008. Save the date! For more information, check their website.

**IOWA CAREGIVERS ASSOCIATION HUB NEWSLETTER**

Look inside for articles, information, and much more...
Please remember to update us if you have any name or contact information changes, so that you can continue to receive the ICA HUB and other program announcements. Thank you.

**Advertising Policy**

Not all information sent to us for publication will be used. Materials or advertising printed in this publication does not necessarily endorse or support the activities of the Iowa CareGivers Association (ICA). All advertising is subject to ICA approval. We do not run job listings. We do run side promoting facilities or agencies and any special programs for CNAs or other direct care workers which would be of special interest to our members and other readers. If you would like to submit materials or ask for publication, please contact us at 515-248-8867 or by email at information@iowacaregivers.org.

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**Iowa CareGivers Association Newsletter:** Delivering information to those who are at the center of quality care

**Special Edition June 2008: Dementia Care**

**Dementia Education Important for all Caregivers**

You are waking up for the day. You are in a strange room and there is a stranger standing over you. How scary is that? There are 5.2 million Americans dealing with Alzheimer’s disease each day, of this number 65,000 are Iowans. Every 71 seconds there is a new case. For many diagnosed with Alzheimers this is just an example of what they face each minute of each day. Many are in Memory Care Units throughout the state and rely on Direct Care Workers (DCWs) to help them with their Activities of Daily Living (ADL’s). These DCWs are required to attend 6 hours of Continuing Education each year to continue to work in these units. But there are also many of these residents with Dementia and Alzheimer’s disease...Continued on page 6...

**Dementia Care: A Priority for the Culver Administration**

Governor Chet Culver signed into law Senate File 3041 May 7, 2008. This law outlines action to be undertaken by the Department of Elder Affairs and the Department of Public Health (DPH). The Department of Public Health is charged with regularly analyzing and collecting data about the current usage and future service needs of persons with Alzheimer’s disease and similar forms of irreversible dementia by county and age and the availability of caregivers now and caregiver needs for the future. In addition, DPH will examine the availability...Continued on page 6...

**Dementia Education Preceptor Project (DEPP)**

In 2007 the Iowa Legislature appropriated $60,000 to be used for dementia specific education for direct care workers and other providers of long term care. The legislation required that funds enhance existing or scheduled efforts through the Iowa CareGivers Association and the Alzheimer’s Association and other organizations identified as appropriate by the Iowa Department of Elder Affairs.

This legislation eventually led to the development of a unique dementia education program in Iowa. The “Dementia Education Preceptor Project”, a collaborative endeavor between the Alzheimer’s Association, Greater Iowa Chapter and the Iowa CareGivers Association, features 24 hours of dementia education over three days. Participation was by invitation and required individuals to agree to serve as a preceptor...Continued on page 4...

**You Said You Need More Education on Dementia Care Your Voices Have Been Heard**

As direct care workers (DCWs) you serve the care and support needs of Iowans with Alzheimer’s and memory loss from other causes. This special edition of the Hub is the result of a partnership between the Iowa Department of Elder Affairs (IDEA), Alzheimer’s Association- Greater Iowa Chapter, and the Iowa CareGivers Association.

More importantly, what you will read in this issue is a response to your voices. You told us that you need and want more education and training on how to provide care and support to those with dementia and their families.

Continued on page 6...

**Inside you’ll find more on dementia care, the DEPP Project, and important resources.**
Dementia is a term used to describe loss of memory and other cognitive abilities that are severe enough to interfere with a person’s daily life. Some of the cognitive abilities that may be affected include speech, comprehension of spoken/written language, recognition/identification of objects, motor activities, sensory function, comprehension of tasks, abstract thinking, and making sound judgments.

Dementia is caused by a variety of diseases or conditions that damage the brain. Alzheimer’s disease is the most common form of dementia, accounting for 60 to 80% of cases.

Alzheimer’s disease is the most common cause of dementia. It affects an estimated 5 million Americans over age 65, and 10 million Americans age 75 and older. Alzheimer’s disease is a brain disorder that slowly destroys memory and thinking ability, leading ultimately to the inability to carry out even the simplest tasks.

Tips on being a Successful Dementia Care Provider:

- Empathize and recognize what the experience of Alzheimer’s disease is like for those affected.
- Know the abilities of the persons that you care for and pay less attention to what they are unable to do for themselves.
- Understand the basics of Alzheimer’s disease as a foundation for good caregiving skills.
- Know the life stories of the people for whom you care.
- When a problem arises, remind yourself that many behaviors result from attempts to communicate needs and cope with the world of Alzheimer’s.

There are many names applied to models of care for persons with Alzheimer’s and related dementias. Activity Based Care, Best Friends Approach and Needs, Environment, Stimulation, and Techniques (N.E.S.T) are examples of approaches to guide us in providing dementia care.

What do these various approaches have in common? Each one stresses the absolute necessity of knowing the person for whom we are caring. A person affected by Alzheimer’s follows an individual course throughout his or her illness. One might experience rapid declines in functional ability while another will progress slowly. A person may lose language skills early in the disease, while another can express needs verbally for years.

Each person has a unique life history, values, attitudes and traditions. However, the person with Alzheimer’s does have the same feelings and emotions as someone who does not have the disease. Affection, recognition, empathy, dignity and feelings of self-worth are basic needs for a person impacted by Alzheimer’s.

For these reasons of individuality yet commonality, caring for people with Alzheimer’s are not task oriented but person oriented. They know the life story of the person for whom they are caring.

Direct care staff who are successful care providers for people with Alzheimer’s are not task oriented but person oriented. They know the life story of the person for whom they are caring.

In Iowa...

in 2008, as many as 5.2 million people in the United States are living with Alzheimer’s disease.

In 2000, there were about 65,000 people with Alzheimer’s disease, by 2010 estimates are that 69,000 will be affected.

Nationally...

in 2008, as many as 5.2 million people in the United States are living with Alzheimer’s disease.

Statistics from a report by the national Alzheimer’s Association, “2008 Alzheimer’s Disease Facts and Figures.”

Dementia Care….No Matter What You Call It

by Ann Riesenbarg, Program Director, Alzheimer’s Association – Greater Iowa Chapter

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Direct care staff who are successful care providers for people with Alzheimer’s are not task oriented but person oriented. They know the life story of the person for whom they are caring.
The Department of Elder Affairs has the responsibility to “review trends and initiatives to address the long-term living needs” and how to meet those needs of persons diagnosed with Alzheimer’s disease and other forms of irreversible dementia. Furthermore, D EA is to “expand and improve training and education” for occupations that interact frequently with people who have this diagnosis and implement public awareness and education efforts. Senate File 2341 is the initial step and a result of the recommendations made by the Alzheimer’s Disease Task Force. This was a collaborative effort coordinated by the Department of Elder Affairs which included legislators, physicians, service providers, industry representatives, aging advocates, and other state departments. The task force met in 2007 and submitted recommendations to Governor Chet Culver and the Iowa General Assembly in January 2008 pursuant to Senate File 489. To access details regarding the Alzheimer’s Task force go to: http://www.state.ia.us/elderaffairs/living/AlzheimersDiseaseTaskForce.html.

It is recognized that this initiative will provide direct care workers information and tools that would aid them in the important care provided for persons diagnosed with Alzheimer’s disease and other irreversible dementias. D EA is concerned about and supportive of direct care workers ongoing desire to be better informed in order to meet the needs of all Iowans.

**Who provides care to those with Alzheimer’s and dementias?**

The 2008 Alzheimer’s Disease Facts and Figures report indicates that close to 10 million Americans care for people with Alzheimer’s disease or another dementia.

Estimates for Iowa in 2007 were that 95,733 informal caregivers provided 82,636,586 hours of unpaid care per year at a value of $874,295,079 to those who had Alzheimer’s or another dementia.

When family, friends, neighbors, etc. can no longer care for their loved ones at home, they turn to professional caregivers like you in a variety of health and long term care settings to provide that care.

**Basic Communication Techniques in Dementia:**

- **Approach the person slowly from the front; speak only when he or she can see you**
- **Remove all distractions – shut off television, music and radios**
- **Position yourself at eye-level with the person**
- **Keep your interactions one-to-one**
- **Use words sparingly; gestures, pictures, pointing to objects are helpful**
- **Give the person time to respond (at least 20 seconds before you repeat your message)**
- **Repeat yourself using the exact same words**
- **Always maintain a smiling face and a gentle tone of voice**

**Dementia Care: A Priority for the Culver Administration**

Continued from page 1...

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**Difficult Symptoms...Problem Solving Strategies**

by Jan Rosenberg, Program Director, Alzheimer’s Association - Greater Iowa Chapter

There are many difficult symptoms that can occur with someone who has Alzheimer’s. Sometimes, symptoms can happen because of the changes in the brain due to the disease. Other times, events or factors in the environment are triggering the symptom. In some instances the task, such as taking a bath, may be too complicated. It might be that the person just isn’t feeling well.

It can be very helpful for caregivers to try and determine why the person with dementia is behaving in a certain way. This may lead to identifying ways to prevent these difficult symptoms from occurring again.

Potential causes for difficult symptoms can usually be grouped into four categories:

- Physical or emotional problems like depression, constipation, pain, fatigue or the effects of certain medications
- Environmental issues such as excessive stimulation, clutter, poor sensory environment, or a space that is unfamiliar or too large
- Causes related to the task if there are too many steps, or if the task is not modified for increasing deficits or unfamiliar to the person with dementia
- Poor communication which can lead to not being able to make needs known or to understand what is expected of them

Caregivers should ask themselves when does the problem happen? Examine what was going on just before the difficult symptom occurred. Review the four categories of causes and try to determine specific triggers such as illness, a noisy environment, the task or the communication between the affected person and the caregiver. Create a list of alternative ways to respond to the symptom and remember that it is a process of trial and error. Reassure the person after an upsetting episode. Caregivers should let the person know that their feelings are understood and that they are still going to be cared for and kept safe. Keep in mind that the difficult symptom is happening because the person with Alzheimer’s is trying to communicate in the face of organic brain disease...it is not happening because the person is stubborn, nasty or trying to irritate you!
To other direct care workers in their respective facility or setting upon completion of the program. Additionally, employers were required to support this program in several ways and to assist with evaluation of its impact on the quality of dementia care.

Classroom education was conducted at four community colleges - Des Moines Area Community College (Ankeny), Hawkeye Community College (Waterloo), Northwest Iowa Community College (Sheldon) and Southwest Iowa Community College (Creston). In each setting, up to ten participants spent four hours per day learning about quality dementia care. Following this classroom instruction, participants traveled to a nursing home to practice what they learned under the supervision of a clinical instructor. Participants also received books, DVDs and other supportive materials for resources to be used in their work settings.

“This intensive combination of classroom instruction and hands-on experience is a unique approach to dementia care,” said Ann Riesenberg, Program Director of the Alzheimer’s Association, Greater Iowa Chapter. “We believe that allowing students to immediately apply the principals and concepts taught in the classroom to the actual care of persons with dementia will improve the quality of that care. It is also important to have role models and resources in dementia care settings to address the challenges associated with caring for those affected by Alzheimer’s and related dementias.”

The four education programs were completed in March and participants are now sharing their new knowledge with co-workers in their respective places of work, such as nursing homes, assisted living facilities and adult day centers. In May, administrators and directors of nursing will complete an evaluation of the program and its impact on care for persons with dementia.

The Dementia Education Preceptor Project was funded as a demonstration project and additional funding from the Legislature is unlikely. However, due to the early success of the program and community college interest in making an ongoing program, efforts are underway to repeat the program and expand it throughout Iowa.

**Education: Small Steps Lead to Wonderful Destinations**

Alzheimer’s is affecting the lives of many Iowans; along with the individual affected with this disease is the family. Health care workers as well as family of people with Alzheimer’s and dementia related conditions desperately need awareness and education in order to successfully care for and understand the disease process.

Through DEPP, Dementia Education Preceptor Project ICA had the opportunity to work with the Alzheimer’s Association and share knowledge to approximately 40 preceptors, who in turn serve as a resource person to their organization. The first ever curriculum that included a clinical component to the classroom education was a welcome prospect, one that was exciting and at the same time had the potential for many challenges. My experience in the clinical setting was remarkable. The student preceptors applied the morning classroom sessions to the afternoon clinical setting. Guidelines were developed to observe and to think about the individual person they were caring for and ways to think out of the box and become creative in care, to develop and provide additional person directed care, and to better understand the world of dementia.

This experience hopefully will open more doors and opportunities to learn and grow, to reach out and care for people with this disease and to provide the best quality of life we can give. Small steps lead to wonderful destinations.

**What is a Dementia Care Preceptor?**

A dementia care preceptor is an experienced and knowledgeable direct care worker who has received formal training to be in this position and who serves as a role model and resource person to fellow dementia-care providers.

**Added Challenge of Working with Mental Retardation and Developmental Disabilities (MRDD) and Alzheimer’s**

Since I have been a member of ICA my life has changed in many ways, a few years ago at the end of one of the ICA conferences it was suggested to me that I should apply to become a member of the leadership council they were forming, I did and was accepted, subsequently I attended the first leadership Training. After that and since being a member of the council I feel I have truly grown in leadership by speaking up about the issues that affect direct care staff and listening to others and what they have to say. Many of you know my main issue has been Health Care Coverage, and that will continue to be my main issue, until it is changed.

But I made a comment that I was asked to talk a little bit about, it involves the setting I work in, which is MRDD. I made the comment that I work with several residents that have Down Syndrome and as the Medical field has improved in technology their life expectancy has been extended, and they are now discovering that many of them may develop symptoms of Alzheimer’s or dementia. We have seen some signs of this in our residents with Down Syndrome, and at times it can add to the challenges of helping them. It tells me that maybe we need continuing education for this in settings other than just working with elderly. I think there are many issues concerning education for direct care staff and the settings we work in. There are many variables. I bet many of you have some I haven’t thought of. If you do send an email or a letter to Pam and maybe she can put yours in the Hub as well and together we can work on getting some education for the things we work with in our daily jobs.

In closing, the things that make continuing to work in direct care grating are the rewards I get from the residents, the smiles, the hugs, sometimes just the sparkle in their eye tells volumes! In May I will have worked in direct care 20 years, most of that time has been in the MRDD setting. It’s not so much that I love my job, but that I love the people I help to care for!

**Education for Caregivers**

who are on the floor with the general population. Their caregivers don’t have the added training to care for their special needs. The 2008 Direct Care Worker Task Force on DCW Education has recognized this need and will be recommending that there be added training for all new DCWs on Dementia and Alzheimers - the disease and care of.

There are also countless family caregivers taking care of their loved ones in their own home. The Alzheimer’s Association is sponsoring support groups to give them the support and education to help cope with this disease process.

My Grandmother had dementia due to mini strokes. She didn’t remember our names, that wasn’t important - but her face lit up when we would come to visit. She still knew us. We have a former coworker in our home, and she too lights up each time we go to the unit. She doesn’t know my name - but that’s okay. When she smiles and her arms go up for that hug, I know she knows me. That smile and hug is all the reward I need. Thanks to all of you taking care of our beloved Iowans who face dementia and Alzheimers disease each day. God Bless You.

*Statutes taken from the 2008 Alzheimer’s Disease Facts and Figures.

**The Need for More Education on Dementia and Alzheimer’s Disease**

In gathering information for the Alzheimer’s Task Force work, the Iowa Department of Elder Affairs heard the need for both public and professional education repeated over and over again from families, consumers, caregivers, health professionals, and others.

Research findings reported by the Iowa Better Jobs Better Care Coalition and AARP Iowa support the need for more dementia specific education and training:

- Only half of the Certified Nursing Assistants (CNAs) who have worked in a Chronic Confusion and Dementia illness (CCDI) unit report that they have taken the required 6-hour Alzheimer’s/CCDI training course.
- Only about two-thirds of CCDI administrators/licensed nurses believe that the required 6-hour Alzheimer’s training course prepares CNAs to provide high quality dementia care.

In my experience in the clinical setting was remarkable. The student preceptors applied the morning classroom sessions to the afternoon clinical setting. Guidelines were developed to observe and to think about the individual person they were caring for and ways to think out of the box and become creative in care, to develop and provide additional person directed care, and to better understand the world of dementia.

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Dementia Education Preceptor Project

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• Only about two-thirds of CCDI administrators/licensed nurses believe that the required 6-hour Alzheimer’s training course prepares CNAs to provide high quality dementia care.

In reviewing this data, it became clear that there is a need to educate caregivers on the importance of education. Iowa CareGivers needed to share this information to Iowa caregivers.
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You should feel good about sharing your voices. This is just one example of how you can have a positive impact on your career in caring and the quality of care you are able to provide to those you serve.

Please watch the Hub and the ICA website for future information about this new educational opportunity for direct care workers and other long term care workers.

Dementia Care: A Priority for the Culver Administration

Continued from page 1...

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“Women are more likely than men to have Alzheimer’s and other dementias, primarily because women live longer, on average, and their longer life expectancy increases the time during which they could develop the diseases.”

“2008 Alzheimer’s Disease Facts and Figures”

Alzheimer’s is the seventh leading cause of death in people of all ages, and the fifth leading cause of death in people age 65 and older.

“2008 Alzheimer’s Disease Facts and Figures”

- Approach the person slowly from the front; speak only when he or she can see you
- Remove all distractions – shut off television, music and radios
- Position yourself at eye-level with the person
- Keep your interactions one-to-one
- Use words sparingly; gestures, pictures, pointing to objects are helpful
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- Repeat yourself using the exact same words
- Always maintain a smiling face and a gentle tone of voice

Basic Communication Techniques in Dementia:

Dementia and People with Mental Disabilities:

- With more people who have mental disabilities living longer, more incidence of dementia is being seen in the population. Alzheimer’s Disease and dementias may appear differently in people with mental disabilities and some of the cognitive changes that occur may not be as readily apparent.
- Look for more on this topic at the ICA Annual Conference, September 8 and 9, 2008 at the Sheraton West Des Moines Hotel.
ALZHEIMER’S ASSOCIATION

24 hour help line: 1-800-272-3900
www.alz.org

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Ph: 319-294-9699

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1730 28th St
West Des Moines, IA 50266
Ph: 515-440-2722

Midlands Chapter- Omaha, NE
1941 S 42nd St, Ste. 205
Omaha, NE 68105
Ph: 402-502-4300

AREA AGENCIES ON AGING IN IOWA

www.iowacaregivers.org

IOWA CAREGIVERS ASSOCIATION
1117 Pleasant Street, Ste. 221
Des Moines, IA 50309
Ph: 515-241-8697
Fax: 515-241-8587
Email: information@iowacaregivers.org
Website: www.iowacaregivers.org

IOWA FAMILY CAREGIVER PROGRAM
Website: www.iowafamilycaregiver.org
Phone: 866-468-7887

IOWA DEPARTMENT OF ELDER AFFAIRS
Jessie M. Parker Building
510 E 12th Street, Suite 2
Des Moines, IA 50319-9025
General Number: (515) 725-3333
Website: www.iowa.gov/elderaffairs/

LIFELONG LINKS

Connecting you to Iowa’s aging and disability resources
Website: www.lifelonglinks.org

AREA AGENCIES ON AGING IN IOWA

www.iowacaregivers.org

For more information on the Alzheimer’s Task Force and to download the final report from the Task Force, visit the Iowa Department of Elder Affairs Website at www.iowa.gov/elderaffairs/

To view the Direct Care Worker Task Force Report, go to www.iowacaregivers.org or http://www.idph.state.ia.us/hpcdp/common/pdf/workforce/dcw_taskforce_1206.pdf

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Announcements:

**June is Iowa Caregivers Month:**
You still have time to honor direct care workers. Check the ICA Website to learn how you can honor direct care workers. You'll find the 2008 proclamation language, a press release and much more. You can now also submit your “Touched by a Caregiver” Story on the ICA website. Go to www.iowacaregivers.org to find out more.

**September 8 and 9, 2008**
- Iowa CareGivers Association Annual Conference “Recipes for Care...Well Done” (Look for the brochure/scholarship application soon)

Remember to visit our website for announcements, program information, and resources. [www.iowacaregivers.org](http://www.iowacaregivers.org)

Alzheimer’s Association-Greater Iowa Chapter will be holding their fall conference on October 16, 2008. Save the date! For more information, check their website.

**IOWA CAREGIVERS ASSOCIATION HUB NEWSLETTER**

Look inside for articles, information, and much more...

Please remember to update us if you have any name or contact information changes, so that you can continue to receive the ICA HUB and other program announcements. Thank you.

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