

BROOKDALE *Respite Reporter*

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A delightful story is spun from this quirky picture by the participants at Friends of the Salem Senior Center, in Salem, Oregon.

Baby In A Briefcase

The baby is sitting in the briefcase and has a bottle of milk in there.
 The baby is happy but not near as happy as he makes you believe.
 He has a lazy eye and looks like he could get into mischief real fast.
 The baby's name is One-Eyed Pete and he thinks he is going on a trip with Daddy.
 One-Eyed Pete needs an eyeball mechanic.
 The mechanic is going to toss his eye up in the air and catch it.
 One-Eyed Pete is a tax man, Otto said.
 Edna hopes there are diapers in the bag, One-Eyed Pete can piddle on the papers!
 Mr. Fudd, One-Eyed Pete's Dad is taking him to Grandma's house.
 One-Eyed Pete lives in Salem, Oregon. It must be warm outside
 because the baby doesn't have any clothes on.
 Bob says they are going to Little North Fork because it is easy to get to.
 You can drive up there and get right back down, Philip says.
 They are going to go swimming and the baby will wear a life jacket.
 One-Eyed Pete got into the briefcase because nobody was watching him.
 One-Eyed Pete's mother is in the kitchen cleaning it up.
 Their dog, Cocoa made a mess in the kitchen.
 One-Eyed Pete and Cocoa are good friends and they get into a lot of trouble together!

This is an excerpt of a story based on the TimeSlips storytelling process that took place at the Friends of the Salem Senior Center in Salem, Oregon. Evelyn Ostermann, the Respite Coordinator, shares the mutual enjoyment, "there was a gentleman who would come alive during one of our sessions. Sometimes, he would chat with another gentleman among themselves and cook up some wild stories!"

Creativity and Dementia: Keeping Open a Window to the Self

by Evelyn Yuen, TA Resource Manager

"Finally, the words just disappear. Alzheimer's erases them from the brain so completely that the names of mundane objects like "pen" or "watch" cannot be spoken. As his illness began and progressed, before diagnosis, Dr. Shearn turned more and more to painting... He reaches through the fog of his dementia, where the glorious words he once mastered are obscured, and he connects still - in this inventive way, through this new medium." - Dr. Kate Scannell, author of "Death of the Good Doctor"

Alzheimer's and related dementias are often associated with a slow descent into oblivion, as words and memory disappear, and a person's self becomes unrecognizable. "I saw people without a role to play, people others

found to be without a self," says Dr. Anne Davis Basting, who founded the TimeSlips Project. Basting, Director of Center on Aging & Community, University of Wisconsin at Milwaukee, is the

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Creativity and Dementia: Keeping Open a Window to the Self *Continued from page 1*

author of *TimeSlips Creative Storytelling with People with Dementia* and also the coauthor of *The Arts and Dementia Care: A Resource Guide*. TimeSlips is a creative storytelling process designed to offer people with Alzheimer's and related dementia an avenue to express themselves without the embarrassment, frustration and confusion often associated with memory loss. Through creating stories based on the imagination, TimeSlips "emphasizes the renewal and meaning that are possible in this time of life."

Luther Manor Adult Day Center in Milwaukee, Wisconsin hosted weeks of storytelling workshops during the development of the TimeSlips Project. In the storytelling sessions that engage participants in a fun and dynamic process, facilitators ask open-ended questions about an evocative picture. When the participants' responses are woven into a story, the results are surprisingly imaginative and always delightful. Participants feel that they have a specific role in a specific time and space, which also helps the staff facilitating the sessions learn how to interact with them.



Participants pose with the masks they made for a Mardi Gras day in Mountain Caregiver Resource Center's respite program in Red Bluff, CA.

In TimeSlips storytelling, one can use any words, say anything, and there is no right or wrong, allowing everyone to participate on equal

ground. New relationships are forged despite fragmented memories or misplaced words; new paths lead to human connection in the present moment. Basting adds that the creative storytelling process bridges the cultural divide for providers as well as participants. While working with Basting, Beth Meyer Arnold, who directs the Luther Manor Adult Day Center, observed an overwhelming and "magical" response from the participants and staff alike. Convinced that the benefits of such programming can greatly improve the quality of life for families and persons affected by Alzheimer's, she has become a passionate advocate for arts programming in the dementia setting.

"The Stories open the world of Alzheimer's to those of us who live outside of it."

- Anne Davis Basting

Arts activities such as storytelling, painting, and poetry have the unique ability to tap into many right-brain functions that are still intact in people affected by Alzheimer's Disease. While the left brain is able to process speech, time, sequence, letters, and numbers with logic, the right brain responds more towards creativity, visual imagery, sensory experiences, and spatial recognition, with emotion. When participants are guided through creative processes that tap into these abilities, it enables them to build on their strengths, which can lend a feeling of success and a sense of accomplishment. Evelyn Ostermann, Respite Coordinator at the Friends of the Salem Senior Center in Salem, Oregon shares a story at her program of a gentleman who

regularly brings the bound collection of stories from their TimeSlips storytelling sessions and proudly carries it around, reminiscent of the days when he was a respected chemist who carried around a briefcase of notes.

Arts, be it a story, a poem, a dance, or a painting allow anybody, including people with dementia, to become creators. In the publication *Memories in the Making* by Selly Jenny with Marilyn Oropeza, artistic expression is encouraged through paintings and drawings. Jenny founded this program based on the premise that "a person with diminished verbal and organizational skills can still communicate through creating a drawing or a picture." Lori, a regular participant in the art program recounted to her family before Alzheimer's struck, "Everyone has a talent, I just can't find mine." Through her ardent participation in the program as her disease progressed, she was able to "find" her talent. In arts activities, everyone has a talent and every creative expression is a success. Anyone can create something beautiful and tangible on their own, boosting self-esteem and greatly reducing feelings of helplessness. The process and creation can be shared with family, caregivers, service providers and the community at large, leading to a sense of fulfillment and purpose. The participants often express the satisfaction of feeling like they are contributing to society.

"Every artist dips his brush in his own soul, and paints his own nature into his pictures."

- Henry Ward Beecher

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Creativity and Dementia: Keeping Open a Window to the Self *Continued from page 2*

I Can Create!, a collaborative arts activities guide developed by Legacy Health System, Caregiver's Respite Services and Very Special Arts Oregon in Portland, Oregon, lists music and movement as two of the more common arts programming in a dementia-related program. As recent memories become a challenge, music is a way to stimulate some of the "old" memories that still persist. One such activity is Music and Movement, which requires only a few supplies, such as a tape player and taped music of an appropriate era, scarves, paper plates, etc., and is effective with varying levels of dementia. The object is to stimulate some sort of movement with response to the music, first through parts of the body, and then diversifying the movements by using the supplies, such as clapping paper plates like tambourines. One woman in the program, who had remained silent and in a slumped position for several years, suddenly jumped up and demonstrated familiarity with an obscure Japanese hand instrument called the kokiroo, brought out during one of the music and



Staff, participants and caregivers at My Friend's Place in Bangor, ME unanimously express their enjoyment, one caregiver exclaimed with laughter, after learning about the day, "You people are so clever!!"

movement activities. It turned out that she had been in Japan 63 years ago with her husband who was there as a missionary.



Tables at the center are decorated with "pop"-themed paraphernalia – popcorn popper, lollipops in bud vases, soda pop cans, popsicle sticks in bowls, and Rice Krispies boxes.

At *My Friend's Place*, a group respite program in Bangor, Maine, the weekly programming is artfully based on themes that always inspire fun and stimulating activities. Barbara Fister, the Executive Director of *My Friend's Place*, described one particular day in March when the theme was "March winds." Through the collective efforts of their dedicated staff and volunteers, the center was charmingly and skillfully decorated with various wind-themed items – windsocks, kites and windmills, made during one of their movement-oriented activities. Throughout the day, activities such as current events, chitchat, and reminiscing with coffee evoked conversations about the weather, past experiences of tornadoes, and the history of windmills. Fister gushes about how "cute the things that the theme of the day may inspire, and how educational they always are!" On another day when the theme was "pop," skillfully planned activities included making interesting objects

from popsicle sticks to promote fine motor skills, and engaging participants in a movement therapy that involved decorating the room with all pop-themed paraphernalia and tossing popsicle sticks into assorted containers. Afternoon tea and coffee with popovers provoked wide-ranging conversations and debates over the word "pop," evoking such playful sayings as "pop goes the weasel." Fister relates that the staff, volunteers, and herself delight in sharing much laughter and joy together and observing the participants achieve a sense of belonging in a supportive environment that strongly encourages socialization.



Fine motor activities such as kite-making keep the participants engaged on this day when the theme was "March Winds." at My Friend's Place in Bangor, ME.

Arts provide people with Alzheimer's and related dementia with a non-judgmental and supportive environment that enhances self-worth, stimulates memory, and affirms their identity. The human spirit, previously hidden by cognitive dysfunction, is once again revealed, and individuals with dementia are able to express with richness their

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creative energy. Art activities promote a deeper appreciation for both the individual and the collective experience for everyone involved in the process. Even as Alzheimer's and dementia take away, artistic expression remains, like Hope in Pandora's Box, as a way to keep open a window to the self.

*“Life can only be understood backwards; but it must be lived forwards.”
- Kierkegaard*

For information on training in the TimeSlips method, visit www.timeslips.org, or call the Center on Age & Community at UWM (414.229.2740.) For information on *Memories in the Making*, visit www.sanalz.org/help_memoriesmaking.htm. □

An Alzheimer's Care Guide for Carepartners

In the book *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*, author Joanne Koenig Coste introduces a supportive, compassionate approach to carepartnering, based on her direct experiences caring for a loved one with dementia, and her decades of work with elder care professionals and families. The author offers a multitude of practical tips and ideas to facilitate communication and adapt the environment. Examples include using images to supplant words – for instance, a picture of dishes attached to the door of the cabinet where they are stored can enhance independence, and placing a lava light in the bathroom helps to focus attention during bathing. Koenig Coste writes, “These ideas are the basis for the humanistic approach to caring that I call ‘habilitation.’ The literal meaning... is ‘to clothe or dress,’ but I use it in the sense of ‘to make capable,’ which is actually an older meaning of the word. A habilitated person with dementia can live using his or her upper limits of function, intellect, emotion, and spirit.” The book provides professional and family carepartners a framework on which to build a plan of care that fosters self-esteem, addresses the needs of carepartners and celebrates successes.

Five Tenets of Habilitation

1. **Make the Physical Environment Work.** Simplify the environment. Accommodate perceptual loss by eliminating distractions.
2. **Know that Communication Remains Possible.** Remember that the emotion behind failing words is far more important than the words themselves and needs to be validated. Although many losses occur with this disease, assume that the patient can still register feelings that matter.
3. **Focus Only on Remaining Skills.** Value what abilities remain. Help the patient compensate for any lost abilities without bringing them to his or her attention.
4. **Live in the Patient's World.** Never question, chastise, or try to reason with the patient. Join her in her current “place” or time, wherever that may be, and find joy with her there.
5. **Enrich the Patient's Life.** Create moments for success; eliminate possible moments of failure, and praise frequently and with sincerity. Attempt to find humor wherever possible.

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An Interview with Joanne Koenig

Coste, Author of *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease*

The Brookdale National Group Respite Program was fortunate to have had Joanne Koenig Coste as the keynote speaker at the national orientation and training conference in Denver, CO in November, 2004. Although Joanne Koenig Coste is often making presentations on Alzheimer's care and frequently traveling on speaking tours around the country, she graciously agreed to an interview for this publication.

In reading your book, one gets the sense that it is written with love and hope. What has helped you sustain this positive perspective over the years?

The feeling that a few people CAN make a difference. Everytime I make a presentation, there is that one person - someone is going to do things differently because of what they heard. It is the chance to teach people that there are going to be choices all the way through.

In terms of "living in the patient's world," what is meant when you write, "listening to their eyes?"

That is the emotion behind the words that are failing. For instance when you hear "I have to go home," are they really saying "I don't feel safe right now?" The eyes will tell us what is meant. This is a disease of language lost but body language is intact. Each of my four kids told me about a "squint" that I did when I wanted to emphasize a particular point. And then they all demonstrated it! They all knew what that squint meant!

When approached by a family member or carepartner of an elder recently diagnosed with early stage Alzheimer's, what guidance do you offer?

Begin attending a support group as fast as you can. Find the resources in your area. Know what respite is available long before you really need it. The time to look for services is not when you are feeling the strain of caring for your loved one.

Conserving energy is also very important. By using energy to get help and taking good care of yourself, you don't burnout. Use timelines as a tool to help you dole out energy and avoid getting overwhelmed. Break things down into smaller pieces this way.

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Considering Falls in Elders: Reducing the Risk

The fact that falls are the leading cause of injury deaths among older adults, (CDC, 2002) is a sobering reminder for service professionals and family caregivers that fall prevention strategies are essential at care centers and in the home. Consider the following statistics related to falls, compiled and summarized by Regina Mc Clurg, Vice President of Professional Services, [Gerontology Network in Grand Rapids, MI](#). This organization provides education and training on a broad range of topics including fall prevention and has implemented a risk reduction program for elders who attend the adult day centers operated by this agency.

- In 1999 – 31% of all unintentional injury deaths of older adults were caused by falls. (CDC, 2002)
- Falls are the most common cause of non-fatal injuries and hospitalizations for older adults (CDC, 2002)
 - Older adults are hospitalized for falls 4 times more often than for other injuries
 - Women are hospitalized twice as often as men
- For every 100 falls seen in the emergency department (CDC, 2002):
 - 76 were treated and released
 - 23 were hospitalized
 - 1 died

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Considering Falls in Elders

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- Fall related deaths increase greatly with age (CDC, 2002):
 - The greatest increase is after age 50
 - There are 22% more falls by men
 - Age-specific death rates related to falls are higher for men
 - Fall deaths are highest for white men over 75, then white women, then African-American men, then African-American women, then Latinos
- Half of all fall-induced fatalities are caused by traumatic brain injuries
 - Death rate for fall-induced traumatic brain injuries for people 65 and older increased 56% (from 8.4 to 13.1 per 100,000) from 1989 to 1998
 - 18% increase for men
 - 27% increase for women
- 8% of seniors over 70 are treated in emergency rooms for falls
 - 33% of these are hospitalized
 - Of those hospitalized, 50% will need long term care (often a nursing home)
- Hip fractures
 - Up to 25% with hip fractures die within one year
 - Only 50% of older adults living independently prior to a hip fracture were able to live independently afterwards
- Falling often results in a fear of falling which limits activities and increases risks for future falls

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An Interview with Joanne Koenig Coste *Continued from page 5*

Respite service providers often find that “selling” the idea of adult day care is a challenge. What insights do you have to share on this topic?

I think we need to push the information we have to provide a reality check. We carepartners need to hear that if we don't find respite, many of us are not going to make it. The numbers tell us that close to 40% are going to burnout with out help.

We all try to be positive about Alzheimer's, but we have to accept that it is a terminal disease. We can be optimistic realists! In our culture, we live on a diet rich on myth and unfortunately we don't have the facts readily available. Professionals can teach carepartners that when we have respite, when we buy time, we can do a much better job for our loved ones and ourselves. We can heal ourselves for what will come down the road.

Please explain your preference for the term “carepartner” rather than “caregiver.”

I don't think you have to care to be a caregiver. You can be paid to do the work that is involved and leave without even talking to the person. To me, “partner” is a positive word. It connotes working together. The message is “I am going to walk beside you.”

What are some of the benefits of adult day care from your perspective?

Socialization; being in a world inhabited by others. The chance to succeed all day long. At home, elders are surrounded by failures and the things that they can't do any longer. They know that very well. When I visit centers, I see the people rolling the dough. They don't make apple pies anymore, but THEY ARE ROLLING THE DOUGH! Even “loners” blossom. In a good Alzheimer's program we feel our own humanness. Families don't need to be activity directors. They have plenty to do already. These programs are enriching for an Alzheimer's patient and they give carepartners the gift of time to heal themselves.

The best friend of a respite service provider should be a Polaroid camera. Take pictures all day of the wondrous time a loved one is having. These pictures will show what a tremendous positive impact the program is having on the person's self esteem. The smiles and laughter say it all.

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Considering Falls in Elders *Continued from page 6*

The fall prevention and risk reduction strategies employed by [Gerontology Network](#) include: 1) a risk assessment for all participants, 2) closer supervision and standby assistance for all elders at risk for falls, 3) a new exercise program to improve strength and balance, 4) the establishment of fall protocols to be applied in each instance of a fall at the center, 5) a fall-specific training and education program for staff, and 6) the implementation of a falls data collection methodology. These interventions are designed to directly prevent falls, monitor efficacy, learn how to improve upon the prevention strategies that are in place and ascertain what other methods might be added to reach the risk reduction goals established by the program. For example, tracking information for each fall occurrence including where, when, who was involved, the time of day, what medications were prescribed, and what health problems existed provides staff with concrete information with which to formulate additional fall prevention strategies for adult day program participants. □

An Interview with Joanne Koenig Coste *Continued from page 5*

What kind of training is important for staff and volunteers of an adult day center?

Alzheimer's training should be a requirement. There should be a good overview of the disease, teaching communication when verbal skills diminish, a discussion of what families are going through (what is the emotional state of the family members) review of behaviors as a result of Alzheimer's, and the importance of the right environment. In a good Alzheimer's program, behavior is very different in the appropriate environment.

How do you describe the innate drive that remains intact in elders living with Alzheimer's that is discussed in your book?

The emotional level of a person will remain intact in Alzheimer's Disease. These emotions will be grown-up, mature, adult. We can still reach the person on this feeling level. All of the arts and spirituality touch this part of the person and are a regular part of any good Alzheimer's program. Staying at home and watching TV will not reach the person in the same positive way.

I'd like to underscore that the disease doesn't take away someone's dignity. We do. We have to be very aware of how we react to the person inside. I remember how my husband's dignity could be crushed by a visitor's comment about a stain on his clothes or someone pointing out food on his beard. But when he went out for a walk with me and his four kids wearing his hat on backwards, a flowered shirt with plaid Bermuda shorts, he would walk along with all of the dignity in the world. □



*Staff and participant at the
Hands of Grace respite program
in Wauseon, OH.*



A participant enjoying singing at the Hands of Grace respite program in Wauseon, Ohio.

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Announcing the 2005 Group Respite Grant Initiative

We are pleased to announce a Request for Proposals (RFP) to develop new social model, dementia-specific group respite programs for Alzheimer's families. Grant applications are due on **July 7, 2005**. Non-profit organizations and public agencies are eligible to apply. Grantees are funded for up to two years (\$7,500 in the first year, renewable at \$3,000 in the second). Agencies must develop an adult day program that includes:

- Dementia-specific services serving two populations – the dementia participants and their family caregivers;
- Structured activities designed to provide socialization and cognitive stimulation, maximizing remaining functional and cognitive skills according to the needs of individual participants;
- Services provided in small groups (five to 15) outside of the home;
- Professional staff leadership supported by trained volunteers;
- Regular hours of operation, with availability of at least one day per week, four hours per session;
- Individual assessments, care plans, and defined admission and discharge criteria; and
- Access to supportive services for caregivers such as support groups, information and referral services, and education forums.

This service must be a new initiative. Expansion of existing dementia programs or the extension of days or hours is excluded. In addition to direct financial support, grantees receive ongoing technical assistance, and an orientation and training conference.

To receive RFP guidelines, a grant application, and a copy of the publication *How to Start and Manage a Group Activities and Respite Program for People with Alzheimer's Disease and Their Families*, please contact Evelyn Yuen, TA Resources Manager, Phone: (510) 540-6734, Fax: (510) 540-6771 or e-mail: bngroup@best.com. For more information, please visit our website at www.brookdalefoundation.org.

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