



Vol. 9, No. 1  
Fall 2006

Produced under contract with  
Division of Aging and  
Adult Services  
NC Department of Health  
and Human Services

by

CARES,

the Center for Aging Research and  
Educational Services,  
Jordan Institute for Families,  
School of Social Work,  
CB# 3550,  
University of North Carolina  
at Chapel Hill  
Telephone: (919) 962-0650  
Fax: (919) 962-3653  
State Courier: 17-61-04

#### Editorial Board

Carolyn Antone,  
Yadkin County DSS  
Glenda Artis,

Home & Community-Based  
Services/Adult Day Care  
Consultant, NC DAAS

Karisa Derece,  
Alzheimer's and Adult Day  
Care Consultant, NC DAAS

John Eller, Director  
Services for Adults Division,  
Mecklenburg County DSS

Lynn Hardy  
Carolina East

Home Care and Hospice

Kathleen Lowe,  
Education Specialist, CARES

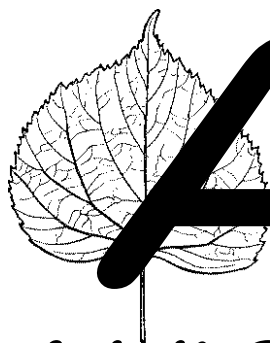
Susie Sprenger, Supervisor  
New Hanover County DSS

Christine Urso,  
Family Caregiver Specialist,  
NC DAAS

Nancy Warren,  
Adult Services  
Program Administrator,  
NC DAAS

#### Editor

Margaret Morse, CARES



# ASPN

## Adult Services Practice Notes

Dedicated to providing information on excellent family-centered practice with adults and their families.

### Helping You Provide Support to Caregivers of People with Dementia

#### Did you know?

- ♦ According to the Alzheimer's Association, more than a third of adults in the US have a family member or friend who has Alzheimer's Disease or another type of dementia. ([www.alz.org/Resources/FactSheets/FSAlzheimerstats.pdf](http://www.alz.org/Resources/FactSheets/FSAlzheimerstats.pdf))
- ♦ Alzheimer's and other dementias affect about 5% of people age 65 to 70, but about 50% of people age 85+. ([www.nia.nih.gov/Alzheimers/](http://www.nia.nih.gov/Alzheimers/))
- ♦ The other 50% of people age 85+ *do not* have dementia. Any change in ability to carry out usual tasks independently should be evaluated by a physician, because there are other common, treatable conditions—depression, medication interactions, vitamin deficiency, infection (which can cause delirium), to name just four—that cause changes in cognition.
- ♦ People who develop Alzheimer's Disease may live 8 to 10 years after diagnosis, and as many as 20 years. (Alzheimer's Association)
- ♦ According to Schulz and Beach, providing care to an adult, especially to someone with dementia, makes the caregiver more vulnerable to disease or death, regardless of any other health condition he or she may have. (*JAMA* [1999], 282:22.)
- ♦ Although half of nursing home residents have dementia, according to the Alzheimer's Association, the bulk of care for people with dementia is provided by their families in the community, and most families bear the cost of home care themselves.
- ♦ Respite—that is, regular relief from caregiving for families to take care of their own needs—helps preserve their health and extends the time they are able to provide care. (National Respite Coalition, [www.archrespite.org/cost.pdf](http://www.archrespite.org/cost.pdf))
- ♦ November is both National Caregivers Month and National Alzheimer's Awareness Month.



### Candlelight Reflections

**A Statewide Evening of Hope to Honor and Remember  
People and Families Affected by Dementia**

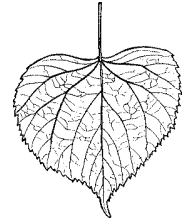
November 1, 2006

To organize or participate in this event locally, visit the DAAS website for suggestions, [www.dhhs.state.nc.us/aging/Alz/candlelightreflections.htm](http://www.dhhs.state.nc.us/aging/Alz/candlelightreflections.htm), or consult your local chapter of the Alzheimer's Association: Eastern Chapter, [www.alznc.org/reflections.php](http://www.alznc.org/reflections.php), or Western Chapter: [www.alz-nc.org/](http://www.alz-nc.org/).

## Resources for Working with Caregivers

November, the month honoring family caregivers and people with Alzheimer's and other memory disorders, provides an opportunity to identify resources, both for professionals who provide services to clients with Alzheimer's and other memory disorders and for families themselves. Although the prevalence of dementia among adults is relatively low in the early 60s, baby boomers are entering the higher-risk years. As they approach 85, they will about double the number of people who currently have it, unless there is a break-through in treatment. Although a handful of drugs have proved helpful to some people with the disease, at the moment, nothing reverses its course. (For more information on current treatments and drug trials, consult the Alzheimer's Association website, [www.alz.org](http://www.alz.org).) And if boomers themselves aren't at immediate risk, many (are you among them?) are confronting the problems of caring for parents and older relatives or spouses who have the disease.

There is a wealth of information on the web. Some you can use to learn more about the disease, some may suggest new skills and strategies for working with caregivers, and some provide tools you can use to help families assess their needs. This issue of *ASPN* gives samples of some of the best we've found.



### Ten Tips for Communicating with a Person with Dementia

1. Set a positive mood for the interaction.
2. Get the person's attention.
3. State your message clearly.
4. Ask simple, answerable questions.
5. Listen with your ears, eyes and heart.
6. Break down activities into a series of steps.
7. When the going gets tough, distract and redirect.
8. Respond with affection and reassurance.
9. Remember the good old days. [Play to long-term and procedural memory, rather than short-term memory.]
10. Maintain your sense of humor.

From *Fact Sheet: Caregiver's Guide to Understanding Dementia Behaviors*. These are just the main points; see the fact sheet for more explanation and suggestions for handling troubling behaviors such as wandering, incontinence, agitation, repetitive speech or actions, paranoia, sundowning, eating, bathing, and other areas.

### Family Caregiver Alliance

[www.caregiver.org](http://www.caregiver.org)

The Family Caregiver Alliance is the lead agency for California's delivery of state-supported services to people of all ages who have disabilities and their family caregivers. Their website is a rich source of fact sheets for caregivers on a wide variety of topics, and the information is available in English, Spanish, and Chinese. Recently added to the website is a toolkit to help practitioners assess the needs of caregivers.

## Organizations That Help People with Dementia and Their Caregivers

### The Alzheimer's Association and NC Chapters

Eastern Chapter, [www.alznc.org](http://www.alznc.org)

Western Chapter, [www.alz-nc.org](http://www.alz-nc.org)

The two state chapters (as well as the national Alzheimer's Association, [www.alz.org](http://www.alz.org)) are important sources of expertise on caring for people who have dementia. The state chapters provide a broad range of resources, programs, and services for individuals with dementia, families, caregivers, volunteers, residential care professionals and health care providers.

### Project C.A.R.E.

[www.dhhs.state.nc.us/aging/ad/NCAIzDemo.htm](http://www.dhhs.state.nc.us/aging/ad/NCAIzDemo.htm)

Caregiver Alternatives to Running on Empty is funded by the US Administration on Aging's Alzheimer's Disease Demonstration Grants to States Program. It uses a consumer-directed, family consultant model to provide respite and other support to caregivers of people with dementia.

Following an in-home assessment, families are helped to resolve caregiving issues, connected with community resources, and provided with funding for respite. Project C.A.R.E. is now available in ten western counties, and there are plans to expand into more counties.

### North Carolina Alzheimer's Support Program

[www.dhhs.state.nc.us/aging/ad/NCAIzheimer.htm](http://www.dhhs.state.nc.us/aging/ad/NCAIzheimer.htm)

This statewide program aims to improve the quality of life of people with dementia and to strengthen the ability of family caregivers to provide long-term care at home by developing a coordinated system of community resources.

### Respite Care Providers

Check with your local department of social services or with the Family Caregiver Support Specialist at the Area Agency on Aging to learn about adult day care and day health centers, in-home agencies, group respite programs, and residential facilities that offer overnight accommodations.

## Duke Family Support Program

[www.dukefamilysupport.org](http://www.dukefamilysupport.org)

This is a one-stop clearinghouse, crisis hotline, and technical assistance center for families caring for people with memory disorders. See their newsletter, *The Caregiver*, which is available free to residents of North Carolina, as well as on line. Also, you may find three documents they have developed particularly helpful, both as sources of information for clients and families and of suggestions about providing excellent care.

### A North Carolina Information & Assistance Toolkit: Working With Family Caregivers of People With Memory Disorders

By Lisa P. Gwyther & Edna L. Ballard  
[www.dhhs.state.nc.us/aging/ad/Duke\\_IA\\_Toolkit.pdf](http://www.dhhs.state.nc.us/aging/ad/Duke_IA_Toolkit.pdf)

Although it was developed for I&A providers, there is a wealth of information in this document for anyone who works with people with dementia and their caregivers. After a review of basic information about memory disorders, the second section offers suggestions for helping professionals, and the third provides information sheets that may be helpful for families.

### “Hit Pause”: Helping Dementia Families Deal with Anger

By Edna L. Ballard, MSW, ACSW  
[www.dhhs.state.nc.us/aging/ad/4545\\_Caregivers\\_booklet\\_3.pdf](http://www.dhhs.state.nc.us/aging/ad/4545_Caregivers_booklet_3.pdf)

Anger, with oneself, or one’s family, or the care recipient, is one of the most difficult feelings that families face, and perhaps the least acknowledged. Directed to professionals, this booklet contains many scenarios that you will likely recognize, with suggestions for how you might respond.

### Wait a Minute!

**When Anger Gets Too Much**  
[www.dhhs.state.nc.us/aging/ad/AngerTips\\_Pamphlet.pdf](http://www.dhhs.state.nc.us/aging/ad/AngerTips_Pamphlet.pdf)

This one-page handout for families reviews some strategies for coping with difficult behaviors. It provides examples of common problems with strategies for managing anger, and the last page contains space for the caregiver to write in the name of someone safe to call who will just listen.

### Some Helpful Reminders about Family Care

(Excerpted from the *Toolkit*)

- ♦ Family care is an adaptive challenge: The family is not necessarily the problem. Few incentives (financial, religious, or counseling) will make an unwilling family assume care. Few disincentives will keep a determined husband or wife from honoring his/her commitment.
- ♦ The “family” is rarely one voice. There is no perfectly fair and equal division of family care responsibility. Most chronic illnesses get worse over time and elders need more help over time. Families can expect a permanent imbalance in the normal give and take of family relationships. Families can still work toward a more equitable sharing of responsibility.
- ♦ There is no one right or ideal way or place to offer family care. Many families are forced to choose between equally unacceptable options. Successful family caregivers gather information, take direct action when it is possible, and often reframe things they can’t change in more positive terms, e.g., “It could be worse—at least I still have her. Tomorrow may be a better day.” (p. 24)

### A Sample Scenario from “Hit Pause”

*Jessie feels that anger is bad and certainly not justified when expressed against someone who is ill, dependent, and can’t help it. She was horrified when she became angry with her father for the first time and heard herself say “I just wish he would die.” Surely she was a bad daughter. She is too embarrassed to talk about these now-recurrent wishes, especially when she is very tired, overwhelmed, or frightened.*

When overwhelmed, the following questions act as circuit breakers to anger or impulsive behavior. These questions are useful in helping the family maintain a healthy perspective about expectations and responses:

- ♦ Do I really need to do, be concerned with, think about, or worry about this?
- ♦ What are the consequences if I ignore this?
- ♦ Am I the only person who can do this?
- ♦ Is this something that must be done now?
- ♦ Why am I doing this? Habit? Tradition? Someone else’s expectation? Guilt? Comfort? Fear of reprisal or objection from the patient?

### A Sample Scenario from Wait a Minute!

*“There are things he does that set me off. ‘He’s doing this to spite me.’ I see them coming and yet, I respond the same way every time.”*

Wait a minute. Count to ten before you respond. This really works. Maybe he needs reassurance, more structure (or less structure), a job, or an activity he can do without the expectation of perfection or standards that he can no longer attain, and appreciation for the things he can still do. . . .

# Continuing Professional Education from CARES

## November 2006

- 1 Working with Clients with Cognitive Disabilities, Pinehurst
- 2 Family Centered Practice, Pinehurst
- 14–15 Geriatric Mental Health, Rocky Mount (and Dec. 5–6)
- 28 Beginning with the End in Mind, Wentworth

## December 2006

- 12–13 Working with Clients with Serious Mental Illness, Kinston

## January 2007

- 9 Working with Clients with Cognitive Disabilities, Winston-Salem
- 10 Family Centered Practice, Winston-Salem
- 17 Substance Use and Older Adults, Greensboro
- 23–25 Effective Social Work Practice with Adults, Whiteville (and Feb. 6–8)

## February 2007

- 13–14 Working with Older Adults and Their Families, Fayetteville
- 20–21 Adult Services Supervisors' Module 5, Smithfield
- 27–28 Adult Services Supervisors' Module 2, Laurinburg

## March 2007

- 14 Ethics and Everyday Practice, Kenansville
- 20–21 Adult Services Supervisors' Module 4, New Bern
- 28–29 Developing Effective Helping Relationships, Louisburg

## April 2007

- 11 Beginning with the End in Mind, Washington
- 17–19 Effective Social Work Practice with Adults, Asheboro (and May 1–3)
- 24–25 Adult Services Supervisors' Module 1, Charlotte

## May 2007

- 8–9 Geriatric Mental Health, Winston-Salem (and June 5–6)
- 15–16 Working with Clients with Serious Mental Illness, Asheville
- 22 Working with Clients with Cognitive Disabilities, Spindale
- 23 Family Centered Practice, Spindale
- 31 Substance Use and Older Adults, Bolivia

## Save the Date!

### Duke's 21st Alzheimer's Conference Strategic Directions in Research and Care

March 1–2, 2007

The Fall 2006 issue of *The Caregiver* ([www.geri.duke.edu/service/dfsp/caregiver.pdf](http://www.geri.duke.edu/service/dfsp/caregiver.pdf)) has highlights of this conference. Look for brochures and registration materials in November 2006.

*Special thanks to Lisa Gwyther, MSW, LCSW and Edna Ballard, MSW, ACSW, of the Duke Family Support Program.*

Visit the CARES web site at <http://ssw.unc.edu/cares/cares.htm>  
for on-line copies of this newsletter, updated calendar of workshops,  
links to background materials for events, and much more.

## ASPN: Adult Services Practice Notes

is sponsored by the North Carolina Division of Aging and Adult Services and published by CARES, Jordan Institute for Families, CB# 3550, School of Social Work, The University of North Carolina, Chapel Hill, NC 27599-3550, State Courier #17-61-04.  
Phone: (919) 962-0650. Fax: (919) 962-3653.  
The NC Department of Health and Human Services does not discriminate on the basis of race, color, national origin, sex, religion, age, or disability in employment or the provision of services. Thirteen hundred copies printed at a cost of \$1,026.00 or \$0.79 per copy.



*The aspen is perhaps the world's largest organism. Although some aspen forests cover acres and seem to be composed of individuals in all stages of life, they share a common root system.*

## CARES

Jordan Institute for Families  
School of Social Work, CB# 3550  
The University of North Carolina  
Chapel Hill, NC 27599-3550  
State Courier: 17-61-04

Nonprofit Organization  
U.S. Postage  
**PAID**  
Permit No. 177  
Chapel Hill, N.C. 27599-1110