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)
- 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/)
- 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)
- November is both National Caregivers Month and National Alzheimer’s Awareness Month.
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.) 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.

Organizations That Help People with Dementia and Their Caregivers

The Alzheimer’s Association and NC Chapters
Eastern Chapter, www.alznc.org
Western Chapter, www.alz-nc.org
The two state chapters (as well as the national Alzheimer’s Association, 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/NCAlzheimer.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/NCAlzheimer.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.
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?  

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
(6–5–6)
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, Ashe ville
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


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.

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