

Alzheimer's Disease, Family Caregivers, and *Faith in Action* in North Carolina

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Seventy percent of the care for individuals with dementia is provided in their homes by family members, according to the National Office of the Alzheimer's Association. For many caregivers, the journey is an isolated one, particularly when there are no local relatives to take a shift or lend a hand. The call to duty rings seven days a week and caregivers have little or no time to tend to their own needs. Many are unaware that programs such as *Faith in Action* can offer respite and emotional support to those caring for loved ones.

Faith in Action, a national initiative of The Robert Wood Johnson Foundation, was launched in 1984, and there are 804 local programs across the United States including Puerto Rico and Guam; 355 serve Alzheimer's patients. Twelve of the 32 *Faith in Action* programs in North Carolina provide non-medical assistance to Alzheimer's patients and respite for their caregivers.

Faith in Action programs organize volunteers from faith congregations and the community-at-large to provide non-medical assistance to their neighbors in need. While programs vary geographically, they share the commonality of the five building blocks that define a *Faith in Action* program. The programs must be

(1) interfaith, (2) volunteer, (3) focus on caregiving, (4) provide assistance in the care receiver's home, and (5) serve individuals who have long-term healthcare needs. *Faith in Action* programs operate under the slogan, "A Neighbor's Independence Depends on You."

According to Larry Weisberg, the director of communications at the *Faith in Action* national office, Winston-Salem, North Carolina, *Faith in Action* programs receive start-up grants from The Robert Wood Johnson Foundation. After the initial funding \$150,000 to 25 grantees in the 1984 and \$25,000-\$35,000 to grantees funded since 1994 *Faith in Action* programs depend on donations from individuals, businesses and other organizations,

and grants to continue to provide services. Programs unable to continue operations beyond the 30-month grant period cited lack of funding as the principal reason for closing, rather than lack of need or lack of volunteer participation.

A survey commissioned by The Robert Wood Johnson Foundation in 2001 profiled *Faith in Action* programs receiving grants from 1993 to 1999. The typical *Faith in Action* program operates with a \$70,000 annual budget. Eighty percent of coalition members are faith congregations and the remaining are from the community-at-large and include civic organizations, businesses, and healthcare agencies. More than 90% of programs provide basic services, such as home visits, telephone reassurance calls, transportation, shopping, and help with household chores. More than 70% care for ill and disabled care receivers, providing respite and hospice care. Volunteers typically serve

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two to three hours per week and 60% of *Faith in Action* volunteers stay with the program more than 12 months.

One role of the *Faith in Action* national office is to help the programs "share best practices," Weisberg said. Technical assistance is provided on volunteer recruitment, coalition building, fund raising and other aspects of organizational development. Volunteer screening and training is the responsibility of the individual programs.

On a national level, *Faith in Action* has established a partnership with the American Association for Retired Persons (AARP). As part of its community service initiative in North Carolina, AARP recruits members to serve as volunteers with selected

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Box 1: Why Do They Do That? – Cursing and Swearing

Two major causes

Language and speech destruction and preservation.

- Alzheimers' patients have trouble finding the right words, saying what they mean, understanding exactly what you mean, and making you understand. As the disease progresses the person has more and more trouble using words. The speech gets vague and lacks specifics making it very difficult to understand. Eventually the person may be able to use only one or two phrases or words for all communication. Ultimately very few words are available. He or she may either speak very little or speak in a 'word salad' making 'no sense,' but keeping some of the rhythms and patterns of speech.
- While the formal language center is damaged early, there are other parts of the brain that are preserved. The first is singing and music. This is why the person can sing all the verses of familiar hymns, or songs, but can't complete a sentence. The second skill is automatic social language and phrases. Things like, "How are you?" "Fine." The third preserved 'skill' has to do with forbidden words and phrases. Swear words are ones that you learned early in life and then stored in the 'don't use these!' areas of your brain and you learned to use other substitute words. Phrases such as "shoot," "gosh," and "darn" became your substituted words when you felt the need to use the spontaneous 'forbidden words.'

Loss of impulse control

- The front of your brain allows you to control your impulses. It causes you to consider the consequences of your words or actions before acting and deciding whether to say it or not based on the possible or probable outcomes. In a healthy person, this part of the brain keeps you from saying something you might regret, and from using the words you are not supposed to use in polite company.
- With the start of Alzheimer's disease, the frontal part of the brain is damaged and then destroyed. The person with Alzheimer's lacks impulse control. If he/she thinks it, he/she will say or act on it. Therefore, Alzheimer's patients may swear and use words that make us uncomfortable or may be completely out of character for that individual. It is critical to realize and remember that persons with Alzheimer's are doing the best they can. They have dementia; it is not a choice they are making.

What Should We Do?

- Always use the positive physical approach when you are helping a person with Alzheimer's disease. Make sure the person is aware of your presence before you begin speaking.
- If a swear word or forbidden word is used, recognize that the person may be frustrated or upset about something.
- If possible, back off a little and give some extra space and time.
- Use empathy and make one of the following statements...
 - ✱ "(Name), it looks like you are getting frustrated with this..." (then wait for a response or agreement or disagreement from the person)
 - ✱ "It sounds like you are not very happy right now..."
 - ✱ "It seems like you are having some trouble..."
- Always remember: You are not this person's 'mother' and you cannot teach impulse control. The brain is dying, and the person is doing his or her best under the circumstances.
- Stop and take stock. Maybe you both need a break before you continue.

Faith in Action programs. Eight North Carolina programs are involved in the partnership: A Helping Hand in Chapel Hill, Care Partners in Greensboro, Center for Volunteer Caregiving in Cary/Raleigh, *Faith in Action* at Work in Burlington, Greene County Interfaith Volunteers in Snow Hill, Care Partners of Mountain Area Hospice in Asheville, Project Compassion in Chapel Hill, and Shepherd's Center of Kernersville. Other *Faith in Action* sites include the following Hospice programs: Center of Living Home Health & Hospice in Asheboro, Hospice of Mitchell County, Hospice of Rutherford County, and Lower Cape Fear Hospice, and LifeCare Center in New Hanover County.

AARP training available to *Faith in Action* sites includes community service programs such as End-of-Life issues, Caregiving, Health and Wellness, Benefits Check-up, Driver Safety, Tax Aide, pharmaceutical affordability, Social Security, and Safe Mobility for at-risk drivers. Some *Faith in Action* program directors have become certified class leaders to conduct "AARP Powerful Tools of Caregiving" workshops. The six-week course

focuses on self-care for the primary caregivers of persons with severe progressive and chronic illnesses, such as Alzheimer's, Parkinson's and stroke. Caregivers learn coping strategies/techniques and are provided with a 'tool box' of resources including publications and information on support groups.

Some *Faith in Action* programs partner with the local Area Agency on Aging to provide in-home respite care. A provision of the Older American's Act, amended in 2000, provides funding for the National Family Caregiver Support Program in North Carolina. This program offers family caregivers a source of information about local resources and offerings, including respite, which may help them provide care for a loved one.

Working with people who have any form of dementia, especially Alzheimer's disease, requires specialized training for the provision of safe and effective service. *Faith in Action* programs and other nonprofit agencies serving the elderly recognize the need to offer additional training to these special volunteers. A basic understanding of typical behaviors, common symptoms,

Box 2: Positive Physical Approach

- Approach from the FRONT - let the person know you are coming
- Go SLOW - reaction times slow as we age - it takes longer for information to register
- Get to the SIDE - be supportive NOT confrontational
- Get LOW - don't use your height to intimidate
- Offer HAND - let the person with Alzheimer's start the interaction
- Call NAME - the name that person PREFERS
- THEN wait.
- Start Message
 - ✱ Give basic information - "It's time to..."
 - ✱ Give simple choices - this or that (orange juice or milk) (eat or go to the bathroom first)
 - ✱ Give single step directions - break down the task (to get up, lean forward, pull your feet in)
 - ✱ Ask the person to HELP you - it feels better to give than to receive!
 - ✱ Ask the person if he or she will at least TRY. Sometimes people will try, even if they don't think they can.
 - ✱ DON'T Ask, "Are you ready?" or "Do you want to...?"
- WAIT for a response (silently count to 10)
IF **NO** response, ask again
- IF Responding
 - ✱ Give positive STROKES - Feedback
 - ✱ "Good job!"
 - ✱ "Yes!"
 - ✱ "That's it"
 - ✱ Smile, nod
 - ✱ Hug, stroke, or rub

and realistic expectations for responses and abilities is critical when developing relationships and offering help and support in these situations. Providing respite volunteers with the essential skills needed to interact and respond to Alzheimer's patients can mean the difference between a valuable, long-term, reliable resource for a caregiver and a one-time disaster for everyone involved. One recommended volunteer training program has been developed by and is provided by the Alzheimer's Association-Eastern North Carolina Chapter. This workshop averages four or five hours and provides the latest information about the various dementias as well as addressing misconceptions and myths associated with Alzheimer's disease. Volunteers are given tools to respond to challenging behaviors by learning more about the disease and participating in hands-on demonstrations and role playing. Faith community volunteers learn that they have the potential to be the bridge between the patient and the family, as well as a vital connector to the larger community.

Role playing and demonstration of behaviors and responses is used extensively in the Eastern Chapter's training of *Faith in Action* volunteers in North Carolina. These interactive and experiential techniques are particularly helpful in teaching volunteers how to cope with challenging behaviors. Lead trainers

demonstrate characteristics and behaviors of a person with dementia. As the trainer approaches, showing impaired speech, memory, understanding, and impulse control, volunteers in training initially watch and react with nervousness, discomfort, and ineffective but typical responses. A very common issue and concern of potential volunteers is the frequent and unexpected use of profanity and vulgar phrases or words by the patients. Many *Faith in Action* volunteers benefit from a clear and simple explanation of this phenomenon, moving it from a 'bad behavior' to one of the very frustrating yet typical symptoms of this disease (see insert 1 for more information). As training progresses, volunteers begin to use the strategies provided and gain skill and confidence in their abilities to make a difference in interactions and client outcomes. By the end of the session, volunteers are able to approach (see insert 2), interact with, respond to, and meet the needs of the person with dementia in a more effective and consistent manner. Long-term feedback from volunteers and family members has indicated that this preparation makes a great difference in the ability of the volunteers to help both the person with Alzheimer's Disease and the caregiver.

Weary caregivers need respite. Medicare and private insurance providers rarely fund such services, yet the use of respite can delay or prevent institutional placement for many elders with cognitive losses. *Faith in Action* programs can provide a valuable resource to community-based dementia patients and their families. These volunteers offer an expanded 'labor pool' that is committed to service. Dementia-specific training and education supports these volunteers and promotes the safety and well-being of all parties involved. Healthcare providers, physicians, physician assistants, nurse practitioners, and other providers can be valuable advocates and information sources for family members and people with dementia. They can encourage the use of respite and reinforce the need for primary caregivers of dementia patients to seek out respite volunteers, which allow them to rest, de-stress, and take care of themselves. A referral to one of the cited resources can show caregivers where to turn for assistance. Increasing public awareness of local resources and supporting these volunteer-based programs will help create an expanding network essential to baby-boomers who become part of the care pool. **NCMJ**

Community Resources

***Faith in Action* National Office**

877-324-8411
www.faithinaction.org

Alzheimer's Association - Eastern NC Chapter

800-228-8738
www.alznc.org

Alzheimer's Association - Western Carolina Chapter

704-532-7392
www.alz-nc.org

AARP North Carolina

866-389-5650
www.ncaarp.org