



Holiday Visiting Tips

A Message for the Faith Community And Friends of Alzheimer's Families



By Edna L. Ballard, MSW, ACSW and J. Whitney Little, Duke Leadership in an Aging Society Intern

Dear Aunt Betty,

I am very happy that you are coming to spend time with Joe and me for the holidays. Our lives have changed a lot in the past months as Joe's Alzheimer's has gotten worse. He is so quiet these days (can you believe that!), he walks slower, and sometimes his speech is hard to follow, but he still enjoys it when people come to visit. He tires easily and may show it by getting upset. He often forgets his table manners and eats with his hands and he will insist on sleeping with that Dodgers baseball hat he's had for decades. It's all part of the disease process. He can no longer control much of his behavior.

When you visit, maybe we can all sing those old songs we used to sing together in Sunday School. Even when he's most forgetful, he can remember the words to many of those, especially the hymns.

Thank you again for coming. I think this is going to be a wonderful holiday for all of us.

***Much love,
Cathy***

As a friend of someone with Alzheimer's disease (or a related dementia) or as a member of his or her faith community, there are many special ways you can bring joy throughout the holidays.

Here is a collection of tips to make your visits with Alzheimer's families pleasant for all.

Contents	Pages
Preparing to Visit an Alzheimer's Family: Old Traditions – New Realities	2
Gifts That Meet Physical, Emotional and Spiritual Needs	3
Visiting an Alzheimer's Family:	
How to Have a Great Conversation When You Don't Know What to Say	4-5
What Does a Good Visitor Look Like?	6-7
Making Nursing Home Visits Count	8-9
How The Church Can Help The Family	10-13

Share these with your faith community and other friends of Alzheimer's families.



Preparing to Visit an Alzheimer's Family: Old Traditions — New Realities

- In advance of a visit, ask about the person's physical and mental condition. The more you learn, the more comfortable you will be around someone with memory problems.
- When visiting, what counts are the moments shared together – not what the person may or may not remember. Sharing time together matters more than what is said and understood.
- Prepare for potentially embarrassing or unusual behaviors (such as the person with Alzheimer's seeing people who aren't there or experiencing sudden angry outbursts.) The person is confused and does not remember what is polite or expected. The offending behavior is because of the disease – don't take criticism or accusations personally.
- Quiet and simple activities are often the best. (This is reassuring to those who think they should be "doing something" – they may never have considered that "just being" is a gift.)
- Keep visits short to avoid unnecessary stress and fatigue for everyone. People with Alzheimer's can usually pull themselves together for a brief visit as long as they get enough rest. Holiday visiting may disrupt the person's secure routine. This can create some stress and anxiety. If the person becomes restless, it may be time to leave.
- Begin new rituals meaningful to the Alzheimer's family at home or in a care facility. Develop a ritual honoring the person with Alzheimer's. Set a place at the table, acknowledge the person in the prayer or blessing, or include a dish that the individual prepared well in the past and provide others with the recipe.
- Choose to celebrate a spiritual aspect of the holiday. Visiting or reaching out to others who are not a part of your family or circle of friends can be a surprisingly healing experience. It gives meaning to the holiday sentiment, "It is more blessed to give than to receive." Elizabeth Hall, author of Caring for a Person with Alzheimer's Disease: A Christian Perspective, shared her meaning of Christmas. Each year Elizabeth would buy a token present for a young man who had returned from the Vietnam War mentally impaired and homeless. His face would light up with such joy at receiving the gift. He, in turn, would give it to the very next person he encountered. "I never felt it was Christmas until I had given him his gift."





Gifts that Meet Physical, Emotional, and Spiritual Needs



“ They presented gifts to Him: gold, frankincense, and myrrh.”

— Matthew 2:11

Giving is a way of showing love, regard, respect, and concern about another’s well-being. Your greatest gift is the gift of self – giving your time, conversation, and expressions of caring, including the willingness to come and “just be.” Listed below are some suggestions if you wish to bring gifts when you visit:

- Useful gifts such as Safe Return bracelets from the Alzheimer’s Association, comfortable clothing, CD’s or tapes of relaxing music or recent church services, videos of friends or family members, gift cards for long distance calls.
- Food items that can be stored and used later when needed.
- 100 stamps and business envelopes to help keep up with bills and mail.
- Laundry basket filled with laundry supplies.
- Respite. "Time off for the caregiver." Volunteer to spend time with the person on a one-time or on a regular basis for a set period of time. For example, once a week, for a month give the family a chance to attend church, synagogue, or other place of preference. A single caregiver may appreciate a companion to accompany him/her to church as well.
- Homemade freezer dinners labeled and dated and in dishes or containers that do not have to be returned. You might also purchase quality gourmet frozen dinners.
- Be creative. Make "errand coupons." One might read, "Coupon good for one homemade apple pie." You may want to add an expiration date so you are not left on hold wondering when or if coupons will be redeemed.
- Provide a cleaning service as a one-time gift, weekly, or once a year, i.e. just before the holidays. Caution: Some gifts may be seen as criticism. Be sure it is something the family wants and will welcome.
- Do not give fish, pets or exotic plants that require attention unless you are certain this is something the person wants. However, a gift for the person’s beloved pet is always appreciated.
- From the church family, a gift Bible signed by persons significant to the caregiver or care recipient such as members of his or her old Sunday School Class, choir, or a personal message inscribed by the minister.





Visiting an Alzheimer's Family

How to Have a Great Conversation When You Don't Know What to Say

We are wonderfully instructed by these excerpts from Henry Walker's poem, "Advice".

...don't go for a conversation
you start,
because your words work for you
and not for her,
her words work for her
and she knows what she's saying
and we should go along for the ride.

Walker, HH (2001) The Maze and Her Path: The Story of My Mother Within the Story
Alzheimer's Tells.

- A person with Alzheimer's may ask the same question over and over again. Graciously answer the question. He or she may have forgotten that the question was asked or may have forgotten the answer.
- If the person with dementia asks you a question that you are not prepared for, offer to find an answer and report back. If the answer to a question might be upsetting, i.e. "Where is my husband?" when the husband has been dead for some time, try to comfort the person by responding to her sense of loss or good memories of her husband.
- Dementia affects people in very different ways. Some people react with frequent tears or with grief, anger, or fear. There are several ways you can respond. You may hug to let them know you care, smile, hold out a hand, ask if they'd like to walk awhile, or start talking about something that might engage or distract temporarily.
- Remember, "An ear is worth a thousand tongues." Sometimes just listening is better than talking...but not always.



Keep Talking by Julee Clark

Excerpts Courtesy of the Western and Central Washington State Chapter of the Alzheimer's Association

People with dementia continue to relate to the world even without words. Most crave the company of people and conversations, even if they cannot participate as well as they once did. They often understand much of what you are saying, or at least pieces, even in later stages when they may be living in a care facility.

KEEP TALKING! Become a good storyteller. Tell the daily stories and happenings of your routine life.

Reminisce out loud about your shared memories. When you tell someone your stories or the details of your life, the person listening feels important. They feel as if they still matter to others.

After years of politely sharing conversation time, and not dominating discussion, **THIS IS YOUR CHANCE!** Feel free to help fill in the gaps of the person's life. Enjoy yourself and remember to laugh at yourself. The more you do this, the easier it will get.

Examples of things you might talk about:

- How you had a flat tire on the way to visit
- Your plans for next year's garden
- A mission project at your church
- The big fish that got away from you
- Your favorite holiday tradition

Fill in your own ideas:

-
-
-
-
-





What Does a Good Visitor Look Like?

*The simplest act of human kindness for a fellow human being
is more important than any refinement of the mind.*

– William Sloane Coffin, Credo, 2004

Notes from a family caregiver

Old Buddies: Otis, my father's best friend, would visit several times a week. He continued to treat my father as if he was still the same old Johnny. Otis had a construction business and sometimes had to go to Montross or Warsaw for materials. He would pick up Johnny just to take him for a ride. Johnny loved Otis. I have seen him turn his pockets inside out and say to Otis, "Man, I am broke, I don't have a dime." Otis would reach in his pocket and give him no less than fifty dollars even though [Dad] probably had forgotten the real value of money.

Mrs. Odessa/Mr. Donald: They came to visit frequently. They are very close friends of my mother. The three of them grew up together. They would come to see if my parents needed anything ...or to just visit and keep my father company and give my mother a break.

The grandchildren: My father loved children and they him. It didn't matter whose children from toddlers to teenagers. One 21-year-old started coming to our house when he was just a baby. [Once he could drive] he would take my father for rides. My father had a special love for his grand- and great-grandchildren. All of them treated him with respect when they came to visit. When his mind would slip, they would continue to talk and joke with him until he would come back around. When he died, every grandchild was at his bedside. Without being able to articulate or even think about it, they showed honor and respect by insisting no one sit in "his chair."

Other friends and neighbors: All of the neighbors and friends would watch out for him if he was outside. He loved to go to 7 eleven where they would give him drinks and candy and other stuff he wasn't supposed to have. He also loved to usher in Church. When he would get confused, the other ushers would go and help him. They would even take him out-of-town when they were invited to usher at another church.

I believe having friends and family who visited him often and who interacted with him the way they always had in the past, along with the Aricept he was taking, really kept him functioning pretty well up until the end...

– Maxine Wilson, Caregiver





Protecting the Person with Alzheimer's from Well-Wishers

- Watch for waning energy brought on by too much activity.
- Watch for fear or anger. Try to protect the person from unrealistic expectations or intrusive questions that the person cannot answer.
- Review below the personal experience of an individual with Alzheimer's.

[Unhelpful] Attitudes Encountered by James

The 'does he take sugar' do-gooders	(I can still remember what I like)
The baby talkers	(Yes I can understand their words but not their attitude)
The whisperers	(Who think normal speech levels might start me off)
The knowledgeable	(Who tell others what I think and how I feel)
The concerned	(Who ask after my health as if I were on a danger list)
The gloom merchants	(Just wait till he...)
The cannots	(You can't do that now or ever – after I just did)
The incredibles	(You manage to go out all by yourself)
The unbelievers	(But you have dementia!)
The monosyllabics	(Who fail to recognize I know longer words)
The well-wishers	(Hope you get better soon)

From: McKillop, J. (2001) *Did research alter anything?* In The Perspectives of People with Dementia: Research Methods and Motivations, Edited by Heather Wilkinson. London: Jessica Kingsley Publishers, 2002.





Making Nursing Home Visits Count

The best visitor comes with a plan to involve the resident and/or caregiver (in conversation or activities). He/she asks questions, pays attention to feelings, never contradicts or explains, and uses gentle humor. When the visit is over, the person with Alzheimer's is happy and relaxed.

Excerpt from Alzheimer's Association of South Australia, 1995 From: Gwyther, Lisa (1995)
You Are One of Us: Successful Clergy/Church Connections to Alzheimer's Families.

- Observe visiting hours. In early morning the person is more likely to be busy with breakfast and personal care. Show consideration for the person's routine, activities, and the interests she may have developed in her new home. If the person loves bingo, that is not the time to visit unless you are going to sit in.
- Visit in small groups so as not to overwhelm the person. If church friends come from a distance and are in a large group, have some members visit other residents while a few spend time with the individual.
- Do not visit if you are sick. This may put the person or other residents at risk. Influenza and pneumonia are real threats to residents during the holiday season.
- Check with the staff to make sure nothing has changed that would prohibit activities or might require special precautions.
- Be mindful that this is the person's home. Be mindful also of the person's roommate and his/her rights to privacy, respect, and courtesy.
- Don't expect to be entertained by the person you are visiting.
- What you might bring:
 - ✦ Holiday decorations
 - ✦ Funny books and cartoons to share a laugh over
 - ✦ Games they enjoyed, such as cards, checkers or word puzzles
 - ✦ Song books or hymnals
 - ✦ Note cards or stationery with stamps to help the person write a letter
 - ✦ Coins and wrappers for a family business
 - ✦ Beans to shell
 - ✦ Fishing videos
 - ✦ A guest book to leave in the person's room for notes from visitors.

Making Nursing Home Visits Count (continued)

- Persons in nursing homes may miss touch and enjoy hair brushing or a gentle back rub. A hand massage with lightly scented lotion may be welcomed. Women may also like having their nails painted and their faces made up. Be careful – the person may have fragile skin or bruise easily. Ask staff before offering massages and manicures. Always ask permission of the person with dementia before you begin.
- Hug, hold hands and sing songs if the person enjoys these.
- Share a meal together in the community dining hall or make a treat in the community kitchen. Slice and bake cookies are simple, fragrant and delicious. Check with staff about any dietary restrictions.
- If you will be making several visits, start a project that you can work on together each time you come. Wrap yarn balls or select quilt pieces for a new baby in the family.
- Include children in visits (bringing with you activities to keep the kids busy). Make sure the person with dementia feels comfortable with children. Also, prepare the children for what they might experience during their visit.
- If the care facility welcomes this, bring your pet to visit. Make sure that the person with dementia is comfortable with pets.
- Visit regularly if you can. If the person enjoys the time with you, your visit has served him well.

Add your own ideas:

-
-
-
-
-

Copies of [You Are One of Us: Successful Clergy/Church Connections to Alzheimer's Families](#), by Lisa Gwyther (1995), are available from The Duke Family Support Program. Download a publications list with order form at www.geri.duke.edu/service/dfsp/dfsp_publication_list.doc or call toll-free 1-800-646-2028.





How the Church Can Help the Family

*Never tell your neighbor to wait until tomorrow
if you can help them now. — Proverbs 3:28*

Notes from a caregiver

Listen, when family members need or want to talk.

- Listen attentively, don't interrupt.
- Accept their feelings without judgment or criticism.
- Maintain confidences when asked, or when your instincts tell you to. (This includes not betraying confidences in prayer groups).
- Don't worry about not being able to answer all their questions, or solve all their problems. They don't expect you to.
- Encourage, but don't stress unrealistic hopes; emotional "roller coasters" can be devastating.
- Recognize their need to grieve.
- Try to balance your concern for both the caregiver and the "patient."
- BE FLEXIBLE. Circumstances often change quickly, so that new needs arise, and old needs no longer exist. Remember, each situation is different.
- OFFER SPECIFIC HELP. It is a good idea to check with the caregiver before initiating any type of service project. They know their situation best.
- BE DEPENDABLE. Never offer any type of help unless you truly plan to follow through. Should you be providentially hindered, try to arrange for a substitute, or at least contact the caregiver and explain what happened.
- IF YOUR OFFER OF HELP IS REFUSED – don't feel personally rejected or assume the person does not want any assistance at all.

–Jennie Lee London, Panama City, Florida
"The Caregiver," Duke Family Support Program





A Message to the Church Community: What's Helpful, What's Not

Bear ye one another's burdens, and so fulfill the law of Christ. – Galatians 6:2

Two are better than one ... for if they fall, one will lift up the other. – Ecclesiastes 4: 9-10

Alzheimer's families often look to the church as a special source of emotional and spiritual strength. For some caregivers who have been forced to give up other interests and activities, the church may be the last source of social contact and respite. These families suggest a number of ways the church community can be supportive.

- Provide occasional relief from care tasks. The caregiver is faced with increased care and housekeeping. Some churches provide meals for a month or a summer of yard work for individuals in need such as people who just had surgery. This is a great model for serving Alzheimer's families too.
- Transportation for the caregiver if he/she doesn't drive.
- Assure non-judgmental acceptance of the family caregiver's style of managing.
- Cultivate community. Spend time but on the caregiver's terms.
- Offer small surprises – a note written on beautiful paper, or a book you read and found meaningful.
- Arrange visits that validate the church's concern for the family. Recognize the person with Alzheimer's disease and his/her caregiver's work and contribution to the church. These visits can bring spiritual solace and practical help to the family.

We can take a lesson from Olga Jones, an RN from Martin County whose experience included working with persons with Alzheimer's. On one occasion, while Olga was visiting a homebound woman, several church ladies came to visit the family caregiver. "They came 'dressed' including white gloves, and sat there waiting to be served tea. I suggested that they get up and find something to do. They took off their gloves and got to work – washing dishes, straightening up ... whatever needed to be done!"

Make a Welcoming Place for the Person with Alzheimer's

I will make a road through the wilderness and give you streams of water there – Isaiah 19

Changes in memory and thinking can be frightening to the person with Alzheimer's disease. It is reassuring to know that despite his declining abilities, the church community still care and will not turn away from him. He may not

What's Helpful, What's Not (continued)

recognize old friends, may not be sure what is expected of him, or he may have difficulty following or joining in the church services. He may do or say things that are inappropriate for church. She may make noise during silent prayer or take money from the collection plate. He may become agitated or upset. Yet the church has a great deal to offer the person with Alzheimer's disease.

For people with Alzheimer's, familiar symbols of faith connect with the heart rather than the intellect. Emotional or sensory aspects of spirituality take on greater significance. For people losing thinking abilities, prayers and hymns become a way to express themselves and receive comfort. The church community can be the connection that triggers rich preserved memories despite the losses imposed by Alzheimer's. Church/clergy can listen and provide continuity, identity, and solace for people with Alzheimer's and their families.

---Lisa Gwyther, You Are One of Us: Successful Clergy/Church Connections to Alzheimer's Families, 1995.

If the person with Alzheimer's becomes restless and disturbs others in Church, most families simply take their relative home or outside until he or she calms down. However, if an usher, nurse or other church staff must help in calming or caring for the person, the following tips may be helpful:

- Use a calm, reassuring approach. "Mrs. Jones, bless your heart and thanks for coming to help us today."
- Make eye contact. Address him by name. Use touch when this is comfortable for you and the person you are addressing.
- Use a low tone of voice while approaching the person from the front. High pitched voices are often difficult to understand and may sound angry.
- Words are not always necessary for communication. Sitting quietly with him while stacking prayer books maybe reassuring and supportive.

All of us need to feel accepted, appreciated, and respected just for being ourselves. The person with Alzheimer's is especially vulnerable and needs even more reassurance. Church leaders can provide a powerful example to the church community in how to relate with compassion and understanding to the person with Alzheimer's and his family.

Adapted from Family Concerns by E. Ballard & G. Cook, Duke Bryan ADRC



Beyond Visits: Church Responses to Alzheimer's Families in the Community

Excerpted from: Gwyther, Lisa (1995) [You Are One of Us: Successful Clergy/Church Connections to Alzheimer's Families.](#)

- Arrange prayer partners for people with Alzheimer's or their family caregivers. Relevant Bible passages can be comforting if they are not presented glibly or as clichés.
- Cards or notes from church members on an occasional basis are the most spontaneous, welcome, least intrusive form of church response.
- Celebrate special Sunday services each month or year honoring family caregivers and frail elders. Consider special accommodations, prayers, escort, transportation, or lunch. Worship services may be adapted with fewer words, using rhythmic hymns, verses, poetry, prayers, benediction, pictures, symbols, old religious objects, or rituals. Sometimes just walking into a familiar church environment will calm a scared church member with Alzheimer's.
- Churches can sponsor retreats for family caregivers with respite care provided to members with Alzheimer's in their own homes.
- Feature one caregiving family a month in the church bulletin to remind members of families at risk of social isolation. The feature could encourage church members to be in touch or list specific preferences or needs of each family.
- Match each Alzheimer's family in the community with one church visitor who commits to check in weekly or monthly. The church visitor might take the caregiver out, drive the caregiver to visit the person with Alzheimer's in a care facility, take them both out, or just bring a special gift like a rose from the church garden.
- Some isolated family caregivers may appreciate new volunteer roles for themselves within the church. Could family caregivers be given telephone responsibilities for welcoming new church members?
- Church men's clubs, youth groups, or circles may choose to adopt individual families. Support teams could be set up to provide periodic home help, errands, or companionship, or to coordinate refreshments, space, or mailings for a support group. See www.SupportTeam.org.





Holiday Visiting Tips

***A Message for the Faith Community
And Friends of Alzheimer's Families***

November 2005

**From the
Duke Aging Center Family Support Program
And the
Education Core, Bryan Alzheimer's Disease Research Center
Duke University Medical Center**

With funding from

The North Carolina Division of Aging and Adult Services

We gratefully acknowledge the review and suggestions provided by the North Carolina Family Caregiver Support Program Director and Family Caregiver Specialists, the N.C. Chapters of the Alzheimer's Association, and the staff of N.C. Project C.A.R.E. (Caregiver Alternatives to Running on Empty), an Administration on Aging Alzheimer's Demonstration Grantee.

