

# "Hit Pause"



## Helping Dementia Families Deal with Anger

Edna L. Ballard, MSW, ACSW

Duke Family Support Program

Duke Bryan Alzheimer's Disease  
Research Center

“Even in the beginning stage when I was so enraged and resentful, feeling all alone, not knowing what to do next, I still knew there were logical, humane, and intelligent solutions to every problem...but I had to get beyond my rage and self-pity before I could see them.” — Shanks, 1996

**As helping professionals, you are in a unique position to help families who feel out of control and out of answers when they get angry with the person who is dependent on them for care, angry with other family members, and even angry with professionals who may appear slow in responding or slow to appreciate the caregiver’s situation.**

# Help!

Families want practical help in dealing with Alzheimer’s disease but also emotional support in dealing with the painful, unpredictable, and often daily assaults on both the care receiver and caregiver as the disease grows worse over time. Here are typical scenarios and suggested responses when helping families develop confidence in their ability to maintain balance under trying circumstances.



**Caregiver scenario:** Beverly Shea, usually warm and pleasant, yelled at her social worker, "Don't give me that 'psychobabble'—I am doing the best that I can, and you don't know him like I do!" when the social worker suggested Beverly try responding differently to her husband's angry outbursts.

Family members may use excellent skills and approaches to care, and yet their relative continues to deteriorate or behave in unpredictable, unwelcome ways. Uninvited advice, suggestions, or instructions may seem like criticism and actually undermine family confidence or self-esteem. Asking "What do you need?" or making a comment such as "What is hardest for you now?" may open up communication for him or her. Do not take the caregiver's moods, rejections, or accusations personally. Recognize "teachable moments" and capitalize on those times when the caregiver is open to accepting help with aspects of care that are difficult or lead to frustration or anger.



**Caregiver scenario:** William Cash, 67 years old, has given up a lot, including taking early retirement to care for his wife for the past three years. He is devoted to her and provides most of her personal care though he has paid help four hours a day, three times a week. His doctor suggested that he slow down after his heart attack last year. He understands the danger but seems unable to let go. He grows more angry and depressed as his wife gets worse.

Acknowledge the loving care he is providing his wife. Families need to be recognized for what they do. Caring is difficult with no prescription or guidelines. Often, the person with Alzheimer's disease cannot say thank you and behaves in a way to make every task harder. Appreciation from you as an objective outsider becomes an important source of support.

Help him set priorities, save energy for the "must do" tasks, and delegate tasks to others. There are wonderful caregiving tips available on getting the patient to bathe, on dressing, eating, or getting the person to go to bed at a reasonable time. Remind him that it is not his fault when even yeoman efforts don't always pay off. "Good enough for now" results really are good enough. *Perfection may not be what's best for the person with Alzheimer's disease.*

Ask "How can I help you balance your and your wife's health needs?" Suggest a support group in his area, especially one with other men grappling with many of the same issues. Help him decide what he once enjoyed and misses most, and start with finding a way to do that one thing a bit more.



**Caregiver scenario:** Jennifer Levy has been tearful in recent weeks while visiting her husband in the nursing home. Finally she tells one of the staff that the fall season now seems so sad because everything important to her and her husband has always happened this time of the year: she and Mr. Levy were married in October of 1947, their only son was born in the fall and was killed 30 years later, three days after his birthday. Fall seems to punctuate what now seems an unbearable loss of everything that was wonderful or major turning points in their lives. Most unbearable, Mr. Levy no longer remembers her. She adds that she wakes up every morning angry at the world that seems to have passed them by.



There is much about this disease that can't be changed or fixed. Be particularly aware of and sensitive to anniversaries that may cause anger or grief. Birthdays, holidays, family rituals, and traditions all can be reminders of better times and bring about feelings of loss or anger at unfairness. Getting angry may be a healthy part of the grieving process.

Help the family explore new rituals, new activities, and new celebrations that take advantage of the patient's remaining interests. For example:

- Your husband loved picnics during those early years of marriage—they can be arranged even now—even in the dead of winter.
- What are other married couples doing now that you miss most?

Acceptance and strength to endure are measures of growth and are often possible with the ongoing support and understanding of trusted professionals. Families need both concrete and emotional help in dealing with complex and unfixable care issues. Sometimes they just need you to listen without judgment.

When communicating with families, it is helpful to avoid particular language and behaviors:

- Jargon, hype, or psychobabble
- Loaded words (*mental health, demented*)
- Assumptions
- Pigeon-holing or trivializing
- Rapid probing of family secrets
- Self-revelations (it's NOT about YOUR mother)
- False promises.<sup>1</sup>

<sup>1</sup> A North Carolina Information and Assistance Toolkit: *Working With Family Caregivers of People With Memory Disorders*, 2002.



**Caregiver scenario:** Jacob Clawson, a big bear of a man, has caused three home care aides to quit caring for Mrs. Clawson because he yells and frightens them. His wife becomes upset during these episodes, and this creates problems, the least of which is trying to calm her down. He refuses to listen to explanations of Alzheimer's symptoms and behaviors or accept suggestions for her care. The nurse supervisor is also uneasy around him, though she believes this is just his manner and that he is beside himself with frustration and anger over his wife's illness.

Mr. Clawson's behavior may be driven by grief, fear, guilt, or any number of emotions that result in behaviors or decisions not in his or his wife's best interest. Not everyone will have the resources, information, or experience to make good decisions. Providing him information that he will find acceptable and useful is a good first step. For some families, this means information at its most basic, such as using the "broken brain concept" by comparing the loss of use in an impaired brain much like the loss of use in a broken arm or broken leg. Explore with Mr. Clawson different kinds of media, including videos, newsletters, brochures, and magazines, as well as support groups that may be helpful.



**Caregiver scenario:** Allie, always timid, always a doormat for her husband and adult sons, all of whom expect to be taken care of, is finally angry. Now, at age 53 with a husband who has dementia, she has a quiet anger and says life is over for her. The rest of her life will just be more "giving" of a different, more difficult kind. How can Allie find a "life of her own" while living up to her expectations of a caring wife and remaining effective in caring for her husband?

Caregivers are often others-focused people, uncomfortable or unable to consider their own needs. Women in particular are sensitive to messages to nurture ill and frail family members, sometimes at the expense of their own needs and interests. Fatigue, frustration, and hopelessness are all seeds for anger. Professionals may be especially helpful by suggesting:

- Respite, help from others, both formal and informal, and increasing private time
- How to protect oneself from criticism or unwanted interference from family, well-meaning friends, or even other professionals
- Assertion and effective problem-solving skill training
- Tips in managing anger, sadness, loss, grief, guilt, and depression
- Sufficient rest, adequate diet, good hydration, engaging social activities, and exercise
- A sense of humor, a capacity for fun, and rewarding yourself for making it work with whatever you have available. Families are notorious for second-guessing their decisions, both big and small.



**Caregiver scenario:** 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?

*Pressure Points: Alzheimer's and Anger.* Ballard, Gwyther, Toal, 2000.



**Caregiver scenario:** "I cannot stand people who have not gone through this telling me with such certainty what I should do. Last week I took the advice of the Alzheimer's patient advocate to let my mom 'do as much for herself as she could.' So I let her do her laundry when she insisted she could. I went to check on her and found the basement covered ankle-high in suds. There was one bra in the washing machine completely twisted around the tub agitator. I was furious."

— Willa, a caregiver for five years

Great advice does not always fit the individual or situation. What works for one person may not work for another. What works for the same individual today may not work tomorrow! There are suggested strategies for Alzheimer's care, but families must be ready and willing to go to Plan B if Plan A doesn't work this time. It sometimes helps to accept this reality if families learn to find humor and perspective. It may take months, even years, before reaching this point. A wife writes "...no caregiver arrives at the same conclusions in the same order or for the same reasons that I have, just as no individual assembles a jigsaw puzzle in the same sequence even if all the pieces are the same."<sup>2</sup>

<sup>2</sup> Beckerman EC. *The Caregiver*. Duke University Medical Center, Summer 1994.



**Caregiver scenario:** "Life is unfair. All our plans out the window! He worked so hard to save for our retirement. Now it all goes for his care. All I can do is watch as he loses all awareness of what's happening to us."

It is sometimes difficult for families to reconcile the tragedy of Alzheimer's—the loss and devastation visited on a beloved family member often seems unjust. It doesn't matter if the person lived a quiet, very circumscribed life or if the person gave much to others, unstinting in his or her time and talents with little or no concrete reward. A sense of randomness adds to fear, helplessness, anger, and the age-old question, "Why him?" There are no easy answers. Rabbi Harold Kushner, in his 1981 book *When Bad Things Happen to Good People*, writes, "When bad things happen to good people, we are troubled by the injustice and the unfairness of life and get caught up in the question of why these things happen." However much time we spend with this question, however many answers we come up with, "the pain and the anguish and the sense of unfairness will still be there." Does this mean we should not ask the question or rail against the unfairness? No. To make the best of our situation, we must, as Rabbi Kushner suggests, "...forgive the world for not being perfect, to forgive God for not making a better world, to reach out to people around us, and to go on living despite it all." (p. 147)

More concrete interventions include encouraging the caregiver to set realistic short-term and long-term goals, such as securing a durable health care power of attorney, getting expert advice about the best Medicare prescription drug program, and making other relevant financial and legal plans. Connect families with organizations such as Area Agencies on Aging (AAA), Senior Health Insurance Information Program (SHIIP), and the Alzheimer's Association. Some caregivers may find guidelines helpful on how to evaluate choices in making decisions.

# Why us?



**Caregiver scenario:** "Don't wake Grandma up for supper; maybe she will starve to death." — a five-year-old overheard whispering to her sister

Children of all ages may be stressed, confused, and angry about this disease and the change, chaos, and uncertainty in the family. Like adults, children also need information and assurances appropriate to their age. Unable to articulate their questions, the result may be behavioral problems or acting out. Older children



also have legitimate anger over changes like giving up a bedroom for a grandmother, maintaining quiet because noise upsets the grandparent, or witnessing traits or behaviors in the family member that bring sadness, fear, confusion, or embarrassment. Refer families to written stories and electronic materials that provide age-appropriate explanations of Alzheimer's and its impact on the family member. *Children need open*

*discussions with adults to give them an opportunity to express their emotions and/or fears.*



**Caregiver scenario:** "He just wet his pants. This is the second time in an hour!" Ellen has been attending a support group, and the facilitator and members of the group have all talked about how important it is to have interests and activities outside of caregiving responsibilities. Recently, she has rejoined her old book club, and this evening they are meeting at her house. Just like last time, Bill seems to do things on purpose that sabotage events that mean so much to her.

Understand the often-competing responsibilities of trying to be a compassionate family caregiver and a gracious hostess. The emotional aspect of providing intense personal care to someone who "appears" capable of doing it himself is difficult. In defense of Bill, his behavior may be due to anxiety or fear brought on by the change in his routine. Another consideration is that there is nothing new or different in the pattern or number of Bill's "accidents." It means something different because the incidents interfere with Ellen's new attempts at self-care, and she is more intolerant of behaviors that don't bother her when alone with her husband. Providing tips on managing incontinence in dementia may be helpful.



The most dedicated, loving caregiver will lose patience and become angry at times. There are a number of risk factors for anger when you provide care: too many responsibilities; difficult, unpleasant tasks; feeling unappreciated; getting little help or support from others; and feeling that "there is no light at the end of the tunnel." Anger under these circumstances is a natural, legitimate response. Anger, however, can cause problems and pain. It can also create energy to seek new answers and inspire new ways of looking at a situation when handled constructively. Finding healthy ways to deal with anger—going for a walk, writing a letter to the offending person and then tearing it up, talking with a friend or a professional, changing those things that trigger the anger, and learning to accept those things that cannot be changed—are some ways to manage the difficult, sometimes frightening emotion.



**Caregiver scenario:** W.C. Brakeman felt a sense of increasing frustration and helplessness. There was so much to do; he felt he was living "a life of interruptions" and not doing a good job. His wife, he felt, deserved better than this. He was able to afford help and willing to listen to advice, but no one seemed to have good answers. He was referred to several agencies which offered nothing relevant to his situation. The small-town living he had once relished now left him feeling imprisoned with no way out.

"Referral Fatigue"—going from one agency to another without good results—can be exasperating. Using the telephone can also be demoralizing. Many caregivers have experienced frustration when dialing for help or information and getting a menu of two or more options from a recording. You may even be cut off at the end or told to try again if you are too slow or hit the wrong button. These families benefit greatly from previews about help available and how to save time when seeking help.

— *Lessons Learned: Shared Experiences in Coping.*  
Durham Alzheimer's Evening Support Group, 1999

Inform families of the unique characteristics of the agency or provider if this information is pertinent to their acceptance of service. Cultural, educational, or social differences may affect whether or not a caregiver accepts a service. When possible, offer a choice of providers.

- Inform providers of your referral to pave the way for the family and to prevent "referral fatigue."
- Prepare the family for any barrier to service, such as waiting lists, limits on the amount of service available, costs, or transportation.
- Anticipate resistance or anxiety about certain services, such as respite or support groups. These services may be unfamiliar to some caregivers. Explore questions, fears, or reservations with the family.
- Pay attention to language and descriptive labeling of services. Remember, words like *respite*, *caregiver*, or even *long-term care* may be unfamiliar or stigmatizing. A wife caring for her husband may not see herself as "caregiver."<sup>3</sup>

<sup>3</sup>Ballard, EL, Cook GM, Gwyther LP, Gold D. *The Physician's Role in Reaching the Reluctant Caregiver*. Duke University Medical Center, 1996.



**Caregiver scenario:** The social worker suspects that Anne is neglecting her mother. Some behaviors are clearly dangerous—for example, locking her mother in the house alone while she goes to the pharmacy and the grocery store. Anne says she has no choice because her mother will wander away. Taking her with her is not an option.

Anne needs concrete information addressing her specific need—someone to stay with her mother while she does errands. Refer her to the county department of social services or AAA caregiver specialist. She may qualify for financial assistance to pay for help. Building a network of neighbors, family members, friends, and church volunteers may be another option. Anne needs information about the risks of the care recipient's wandering and safer ways to address the risks.



**Caregiver scenario:** There is recent friction in the Adams family, especially between two of the sisters—Lettie, who resides in the family home and who is the primary caregiver for their mother with dementia and Laura, who lives three thousand miles away in San Francisco. Three weeks ago, Lettie informed the family that she is exhausted and can no longer care for their mother; she believes a good alternative is nursing home care, especially since the other five siblings say they are not in a position to care for the mother. They insist Lettie should continue since she is unmarried, needs a place to live, does not have a family of her own, and “has done such a good job.” There has been a flurry of calls and letters but no agreement. Lettie is livid with the family's lack of support and concern for her rights and well-being. She has been the sole caregiver for three years now.

Help the family review and choose a solution-seeking strategy. Mediation, brainstorming, or a simple family meeting may help. The primary caregiver may need professional support in making decisions for the care receiver, especially when the person and other family members object to proposals on the table. Other family members may be critical, particularly in the early stages when the person's deficits are not obvious. Often, no matter what course of action is taken, families are burdened with doubts and recriminations. It helps to remind the primary caregiver that there are no “right or wrong” answers for many care dilemmas, and decisions must be made based on consensus with other family members. Begin by objectively examining the issue or problem. Brainstorm possible solutions (do this without criticism of any idea, no matter how implausible it seems). Choose one strategy to try with an evaluation point. For example, short-term respite for the mother in an assisted-living facility would give Lettie a break from caregiving with the added advantage of knowing her mother is in a safe environment. It would offer the family an opportunity to see how



well the mother adjusts to the facility. Indeed, the mother may enjoy being with people her own age and in an environment that does not demand more of her than she is capable of. (Note: Individuals vary in the time it takes to adjust to the new environment; families must not respond prematurely and withdraw the person who seems not to be adjusting.) Consider the consequences for everyone involved. Evaluate. Keep or start again. Accept that the problem may not be solvable now.



**Caregiver scenario:** Lawrence Collins is torn in his feelings towards the local hospital. Twice he's rushed his wife Lorraine to the emergency room, once after a fall and later a bladder infection. Both conditions were handled with top-notch medical skill for which he is grateful. On the other hand, he was frequently frustrated and angry at the nursing staff who should have known better how to respond to someone with Alzheimer's disease. Mrs. Collins was asked to answer questions and fill out forms even after her husband and daughter told the staff that these tasks were beyond her ability. His wife would become agitated because she was aware of her deficits. Twice Mr. Collins found his wife alone and confused in the hallway. His request for a room closer to the nursing station was not honored. Mr. Collins even asked if he could bring in his wife's "comfort" pillow with its field of red and blue flowers faded from a hundred washings. He was told it was against hospital policy. There were other incidents, all minor, that Mr. Collins tried to accept because his wife received such good technical care. Yet, he hopes he never has to take her back to that hospital.

Family stories of hospitalizations are legion. Like Mr. Collins, most families are grateful for the treatment or relief from symptoms, but there is a heavy emotional toll when a family member with Alzheimer's is hospitalized. Mrs. Collins is understandably more confused, frightened, and unable to report accurately or advocate for herself. Tests, sedation, and her dementia increase her risk for delirium or other hospital-induced problems. An excellent guide for families and hospital staff, *Acute Hospitalization and Alzheimer's Disease: A Special Kind of Care*, available from the National Institute on Aging, offers general guidelines, possible causes of typical problems, and suggested strategies to insure good outcomes, reducing the risks of hospitalization for the patient and family.<sup>4</sup>

<sup>4</sup> National Institute on Aging. *Acute Hospitalization and Alzheimer's Disease: A Special Kind of Care*. A companion guide, *Hospitalization Happens: A Guide to Hospital Visits for Your Loved Ones with Memory Disorders* is also available. Both booklets were originally produced by the North Carolina Department of Health and Human Services, Division of Aging, in conjunction with the Joseph & Kathleen Bryan Alzheimer's Disease Research Center.

**Hit the Pause Button:** Many expressions of anger are reflex reactions. Getting beyond changing this reflex response involves substituting another reflex response such as adopting a mantra to use every time the caregiver becomes upset. One husband would simply say to himself “Put it in neutral” when he was exasperated with his wife. Some families will respond to reminders of the age-old advice of counting to ten

before responding. Encourage families to pause and think for a moment: “OK missy, let’s see how you’ll handle this one.” The mantra gives them a moment to think before acting on impulse. Caregivers may be surprised to find that the anger dissipates without further action or thought. If the reason for being upset is justified, the pause is still valuable in choosing a thoughtful response to modifiable sources of anger.

For many families the best option is simply learning to accept that caring for and loving someone with Alzheimer’s disease presents unexpected challenges and difficult adjustments.

Acceptance is not approval, consent, permission, authorization, sanction, concurrence, agreement, compliance, sympathy, endorsement, confirmation, support, ratification, assistance, advocating, backing, maintaining, authenticating, reinforcing, cultivating, encouraging, furthering, promoting, aiding, abetting or even liking what it is... Acceptance is simply seeing something the way it is and saying “That’s the way it is.”

— *You Can’t Afford the Luxury of a Negative Thought.*  
Rogers, McWilliams, 1990

**Call the Duke Family Support Program at 1-800-646-2028  
for more specific help with families.**

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



**DUKE UNIVERSITY MEDICAL CENTER**

Developed for the NC Department of Health and Human Services,  
Division of Aging and Adult Services

With funding from the Administration on Aging for the  
NC Family Caregiver Support Program and Project C.A.R.E.  
(Caregiver Alternatives to Running on Empty)