

## **BASIC COMMUNICATION TIPS AND COPING SKILLS FOR ALZHEIMER'S FAMILIES**

*“We argued every day. Mom said something that was completely wrong or ridiculous and I always managed to correct her. The stress of communicating with her became almost unbearable. Her geriatric doctor made a wonderful suggestion. He said, ‘Go with the flow.’ He said if Mom says it’s time to eat, tell her she is right. Before she has a chance to think about it, I distract her and point out a family picture or a flower in the garden. She forgets about eating, and we move on to the next thing. One day she couldn’t stop thinking about her dog, Jack, who died ten years ago. I remembered what the doctor said, and instead of screaming at her that Jack’s dead and gone, I suggested we try to find him in the yard. By the time we got her coat on, she forgot why we were going outside. It doesn’t always work, but coping with her in this way makes it easier on both of us.”*

Denise, New York

Very few tasks are more stressful for a family member than being an Alzheimer’s caregiver. As you and your family find it more difficult to care for or communicate with your parent, you may be more apt to be angry and frustrated. At the more advanced stages of the disease, you may be caring for someone you’ve known for fifty years, but who doesn’t recognize you in return. Your mother may look at you innocently, call you by the wrong name, and begin to tell you about her daughter whom she calls by the name of your grandmother. Your father, with whom you’ve had a lifelong close relationship and who adored his grandchildren, may ask you who you are and tell you he’s sorry he didn’t have children. It’s easy to understand why depression is so prevalent in

Alzheimer's families. It's also easy to understand the anger you might feel when a parent asks the same question repeatedly even though you answered it seven times in the last five minutes, walks away in response to a request to "sit down, Mom," or even becomes aggressive and actually strikes you with no warning and for what appears to be no reason at all. There is a reason for all these actions and reactions.

We learn by association and memory. When your parent's memory fails, your parent may no longer remember the names of beloved family members, pets, friends, his home address, telephone numbers, eating and personal grooming habits, and all the rest of a lifetime's learning and memory storage. Your parent doesn't remember asking the same question repeatedly (or even once before), may not remember what "sit down, Mom" means, and may act aggressively out of fear, confusion, frustration that she is unable to communicate with you, or simply because that's a symptom of Alzheimer's disease. Because you can't "see" the impaired cognitive function of your parent's brain, your parent may look perfectly healthy. It's difficult for caregivers with normal memory function to imagine living with no memories of as recent a time span as five minutes ago.

A major cause of tension is the lack of understanding of how to handle routine tasks such as dressing, eating, or family gatherings so that problems are minimized. Specific Alzheimer's training and coping techniques are critical to controlling stress levels. Without specific training, usually available from your local Alzheimer's organization or Area Agency for Aging (see chapter 20 for a list of organizations and resources), you may not understand that the reason your parent continues to ask the same question over and over again is because she has no memory of having asked it the first time. You may not realize that angry, hostile behavior from your parent when you insist on a bath may be because your parent has forgotten what water is, and she may

be frightened. Your parent, who practiced modesty for eighty-five years, may be embarrassed to undress in front of a daughter or anyone else.

As your parent's memory and skills decrease, it's important that your knowledge of AD and your coping skills increase. The primary rule is: The more confused your parent feels, the more difficulty you will have communicating and accomplishing even the simplest task. These twelve suggestions will help keep both you and your parent on a more even emotional plane, and that will make routine tasks simpler.

### **1. Remember Your Own Needs**

Get help. Involve your family. Involve healthcare advocates. Involve your physician. Get involved with your local Alzheimer's support groups. (See Chapter 24 for a guide to resources.) Involve your clergy. Alzheimer's disease is the wrong illness with which to become (or to stay) isolated, independent, or alone. The best way to help your parent is to help yourself. Ask the neurologist who performs the testing and presents the diagnosis for a list of resources in your community. Ask the representatives of these resource organizations for assistance, and keep asking until you find the type of help that meets your needs. Stay in contact with the AD community throughout the duration of the illness. Staying current with new research and coping techniques may allow your parent to participate in new treatment options. Also request referrals to the appropriate professionals who will help you obtain the information to make informed decisions as you plan for the future.

*"I feel the support I've been getting is beneficial, but the burden still falls on me. I would recommend anything and everything, the more the better."*

Sharon, Maine

*“Peace of mind is the greatest gift you can give anyone.”*

Annette, Connecticut

## **2. Accept the disease**

People with Alzheimer’s often become less inhibited. They do and say things that can cause us great anxiety because they embarrass us in front of friends and in public places. The caregiver who shared this lesson said it all:

*“I never knew what my father was going to say or do. It didn’t matter if we were in a restaurant, on a walk, or at the doctor’s office. I was always so tense I could hardly breathe. Once, in a mall, he looked at a woman and blurted out, ‘Don’t you own a girdle? You look awful in that dress.’ Another time, in a restaurant, he picked up his chicken breast, smeared it with gravy, put it in his shirt pocket, and patted it down until it seeped through his shirt. I finally learned how to handle it. Now, I just look at whomever he insulted or anyone who’s staring at us, smile, and say, ‘He’s got Alzheimer’s disease.’ Once I stopped keeping the secret, I relaxed. It took me too long to realize that there is no shame in being ill.”*

Arlene, Florida

## **3. Don’t Take Outbursts Personally**

Your parent has not changed from a loving parent (or a nonloving, but reasonably rational person) into a spiteful monster and your parent isn’t trying to get back at you. Personality changes like anger, irrational outbursts, and aggressive behavior are part of this disease. Anxiety,

fear, and frustration precipitate many aggressive outbursts. Affirmation, distraction, and humor are the best tools for you to use to deal with these disturbances.

For example: You know your father has no plans and no visitors are scheduled, however, he suddenly walks up to you and angrily says, *“Tom was supposed to pick me up and he’s late!”* Remember, your father actually believes Tom is late, and he is angry. You might smile, nod your head up and down in affirmation, point to another room in your house, and respond *“Oh, he called and said he was going to be late, but he’d pick you up in there.”* You have every chance that by the time your father reaches the other room, something else will attract his attention, he will forget about Tom, and his anger will disappear. You have just successfully used affirmation and distraction to diffuse your father’s anger.

A more dangerous example is Mary’s tale: *“I had no warning. All of sudden he just lashed out and hit me. I’m afraid to go home. How can I care for him if I’m afraid of him? I don’t know what to do.”* Sometimes the only way to calm your parent down in a situation like this is to briefly leave the room for a few minutes. Again, your parent will likely forget the outburst very quickly unless the trigger is still in place. After the outburst is over, call your parent’s physician and ask for help.

When your parent seems disturbed, try to identify what triggered the disturbance. It may be a high-pitched siren, an inability to understand your request, fear of a stranger, or frustration over a complicated menu. Sometimes the confused person is not only angry, but may be anxious as well. When Fred, a retired seventy-five-year-old farmer with AD, was hospitalized, the nurses found him more anxious at lunchtime than any other time of day. Every time he looked out the window, he became increasingly angry and upset, and refused to eat. The staff was puzzled

because they couldn't distract him. One day they realized that when Fred looked out the window, he saw the lawn furniture and thought he was looking at his cows. They thought about the problem and came up with a solution to relieve his anxiety. The next day when he refused to eat, the nurse acknowledged his feelings and told him not to worry because they had arranged for someone to take care of his cows. Fred was clearly relieved, and he happily went to lunch.<sup>2</sup>

You won't be able to identify or avoid all the triggers, but if you keep a list of stressful situations, you may be able to avoid them, develop ways to deal with them, and slowly reduce the number of outbursts.

#### **4. Keep Your Requests Simple**

The more you prompt and use orienting words and physical expressions, the less confused your parent will be. Because Alzheimer's destroys memory, your parent will find it progressively more difficult to remember the correct response to off-the-cuff requests or commands, and almost impossible to respond to slang expressions. Speak clearly and simply. Use language with identifying words and prompting actions to help your parent understand your request. An unclear request like "*Have a seat*" changes entirely when you touch the chair and say, "*Sit here.*" Another example of unclear language is this double command with sequential tasks: "*Take your sweater off and get ready for dinner.*" You'll have better results by walking over to your mother, smiling, saying "*Let me help you take your sweater off,*" and *gently helping her. Then point to or touch the chair where you want your parent to sit and say "Sit here."* Continue, one request at a time, until you've accomplished your goal. Use the same command each time. Do not change "*Sit here*" to "*Sit down in this chair.*" Your parent has to try very hard to understand any command and do what you ask. If you change the words, your parent will have to start all over again trying to understand what you want.

## 5. Beware of Your Physical Attitude

Alzheimer's does not prevent your parent from sensing fear, anger, hostility, tension, or other negative feelings in other people. These feelings may be recognizable to your parent in the way you stand (shoulders hunched, fists clasped, lips taut, body or voice tense); in your speech (clipped and terse), loud voice, hissed words; and in physical displays or actions (slamming doors, phones, objects, waving hands, your red face, and your eyes blazing with rage). Any of these can easily create fear and confusion. Your parent will recognize your anger, but will not know why you're angry. He will become anxious and will be afraid of you. Reactions may range from tears to striking out at you; certainly all communication will be destroyed, and you will not accomplish whatever you started. The stronger the feelings that you send, the more extreme your parent's reaction will be.

*"I didn't understand why Dad got so upset when we introduced him to his new home health aide. He became aggressive and angry, and he said terrible things to her. At first I thought it was the fact that someone new was in his house, but then I realized exactly what had changed. His old aide was very soft spoken and gentle. The new aide was very personable and made us feel good, but she was much too loud and aggressive for Dad. We talked to her about toning down a little, but in a short time we all realized that she was not the one for this job. When we screened the new aide, we asked her to talk to Dad and spend the afternoon with us. She was calm, and he reacted favorably to her. You live and learn."*

Hilda, Florida

If you feel your frustration boiling over, or if your stress factor has reached overload, make arrangements for a break. A short respite period, even an afternoon off, may help.

## **6. Use Strategies When Eating Out**

If you go out for dinner, don't expect your parent to understand a long list of specials and a multi-option menu. All of those unfamiliar choices in an unfamiliar room will simply bring on confusion, which may turn into fear, which may turn into anger or stubborn rejection of the food or you. Order for your parent by saying, "Dad, I know you like chicken for dinner. I'll order that for you." If your parent insists on ordering, start the ordering cycle with your parent. This may help eliminate the anxiety of waiting to order.

## **7. Avoid Crowds**

You may not notice or think twice about crowds in restaurants, shopping malls, and other public places, but they may seem frightening, confusing, or overwhelming to an AD patient. Help your parent to focus on what you are saying by eliminating all other points of interest. Alzheimer's disease causes increasing problems with focus and concentration, and anything that competes for attention is certain to make understanding and communication more difficult. Try to frequent crowded places at off hours: for example, restaurants before and after peak dining hours, and malls early, late, or at the dinner hour. Your parent should be less anxious and more at ease, which will enable both of you to enjoy the outing more.

Unfortunately, no matter how well planned an outing is, there are always exceptions. A caregiver in Florida reported taking her father to the doctor. This doctor and the staff were skilled in treating patients with dementia, her appointments were always scheduled for

midmorning, the doctor usually saw them immediately, and she rarely had problems during these visits. On one memorable occasion, the physician was late, and Arlene and her father had to wait. Her father kept staring at a heavyset woman in another chair. The woman finally smiled and said, *“Hello. It’s a beautiful day today, isn’t it?”* Arlene’s father answered, *“Hello yourself, you’ve gotten pretty fat!”* Arlene said she apologized and took her father out for a walk. She felt guilty because she was embarrassed and ashamed of her father.

We suggest two words: “accept” and “admit.” Uncensored speech and relaxed inhibitions are often a part of the disease process. Admitting to the people around you that your father has AD and accepting the fact that his behavior is sometimes part of the illness may help you place your parent’s socially unacceptable behavior in the proper context. It is sometimes difficult not to feel that this type of “acting-out” behavior is not payback for something you did forty years ago, but it isn’t. It is not retribution, and it is not happening to you because your parent wants to hurt you or punish you. It is just one aspect of a very difficult and complex disease process. If this type of behavior becomes increasingly difficult for you and your parent, ask your geriatrician, neurologist, or geriatric psychiatrist for assistance.

## **8. Make Appointments for Midmorning**

A part of AD is what is known as sun-downing syndrome, in which the patient is especially prone to act out aggressions, fantasies, or abusive or other uncontrollable behaviors in the midafternoon to early evening hours. Even if there is no sun-downing syndrome present, your parent may just be fresher in the morning. Try to make doctors’, shopping, and other appointments during midmorning, when AD patients are usually more alert and rested, and have more ability to concentrate.

## 9. Make Sure Professional Healthcare Workers Are Savvy about AD

Physical exams, psychiatric tests, CT scans, blood tests, dental work, homecare workers, and even a simple blood pressure reading require special knowledge when working with an Alzheimer's patient. Your parent may have trouble comprehending a standard explanation of the test and may become frightened or even combative. The experience may be traumatic enough to throw off the results of the test, or worse, your parent may become anxious enough to elevate a current level of confusion. When you make the appointment, ask if the physician, nurses, and technicians are experienced in working with AD patients. If not, ask your local Alzheimer's organization for a referral to another professional. It usually takes experience to keep an AD patient calm and comforted while a dentist is treating a toothache or while a technician is drawing blood. If you hire a professional homecare worker or companion, ask about previous Alzheimer's experience. What was the worst experience the homecare worker had, and how did she handle it? This will give you an idea of how knowledgeable the worker is. (See chapter 11 for tips on selecting a homecare worker.) If you doubt your ability to assess the worker's skills, ask someone more knowledgeable to help you.

*“Mom needed some dental work. Her regular dentist refused to handle the situation, because the last few visits were pretty tough on him and her because she kicked the dentist and tried to bite him. We called the Alzheimer's Association and asked for a referral to a dentist who can handle Mom's problems. They provided us with the name of a dentist who spent time talking to Mom, learning about her medical conditions and her medications. Once she had a complete picture, she examined Mom's teeth and said that she needed to give Mom anesthesia in order to do the work. She said she would*

*Speak to Mom's doctors to determine if this was possible and then she would schedule an appointment. Mom received medical clearance, and the dentist took care of her teeth. We really appreciated the fact that she did not dismiss Mom's needs, and found the best way to deal with them."*

Faye, Pennsylvania

## **10. Build in Routines and Encourage Pleasurable Activities**

For an AD parent who lacks memory, eating or dressing may be new experiences each day. You can help your parent feel less anxious and more secure if you create a routine and schedule the same morning, afternoon, and evening activities at roughly the same times every day. As the disease progresses, your parent's ability to participate will be limited, but you can adjust and simplify accordingly. For example: take shorter morning walks; confine gardening activities to one plant, one flower pot, and a small bag of soil; and limit helping with housekeeping to folding two or three laundry items. As short-term memory fades, memories of enjoyable events from earlier years take on added importance. Religious services learned as a child remain comforting; music enjoyed decades ago may bring pleasure because the words and tunes, stored in long-term memory, will still be familiar. Looking at photographs of earlier family life and memory boxes filled with your parent's favorite items are good for stimulating memory. Whether your parent is at home or in a nursing home, feeling appreciated and a part of the family remains critically important. When possible, try to involve your parent in pleasurable activities you both can enjoy together: walking, listening to music, talking, or singing songs. Include your parent in the family's routine as much as possible to make him feel comfortable and loved.

## 11. Use Day-Care Programs

Dementia-specific or Alzheimer's-specific day-care programs can be invaluable for an AD parent and caregiver. Many are subsidized by grants that allow users to pay on a sliding scale, many are free, and some provide transportation. One to three days (or more) each week can help provide stimulating social and mental activities for your parent. For you, it may just provide enough freedom and time off from caregiving duties to make a substantial difference in your life and your family's life.

*“There is no greater joy or pleasure than seeing my dad dance and sing and laugh. When he began to lose his memory and say and do inappropriate things, his healthy friends dropped him as if he had the plague. I always wanted to say, ‘It’s not contagious.’ But he was left alone. Now he goes to day care and this wonderful man has come back to life. I know that some people don’t do as well in a social setting, but this is made for Dad’s personality. He just needed a place that accepted him for who he is today.”*

Theresa, California

## 12. Be Sure to Take Appropriate Safety Measures

Act now. Don't wait for an accident before you take simple safety measures. Intervene at the first sign of impairment.

- Remove scatter rugs and make sure all electrical cords are out of walking areas. An AD parent is many times more likely to take shuffling steps, trip, and fall.

- Call a professional to install railings on stairs and grab bars in the bath or shower so your parent can use them to balance and to avoid falls.
- Add more lamps or change bulbs to a higher wattage if current systems can tolerate the increase. Your parent will need bright lighting to avoid tripping or bumping into table edges.
- Place night-lights throughout the house to help avoid stumbling or falling if your parent wanders during the night. Pay particular attention to stairways.
- Place a safety gate on stairways. Make certain someone is available to open the gate in case of an emergency.
- If your parent wanders, raise the lock on outside-access doors above your parent's reach or Velcro a cloth the same color as the wall over the doorknob. This will make the doorknob almost invisible and keep your parent from opening the door. Do not try either of these or block exits unless your parent has twenty-four-hour supervision to help evacuate in an emergency.
- Make certain chairs are heavy enough to stay put if your parent suddenly "plops" down; many kitchen or dining room chairs can skid out or tip backward and cause a fall.
- As the level of impairment increases, be certain balconies and walkways are only accessible under supervision.
- Secure all medications, even over-the-counter remedies such as aspirin, laxatives, and vitamins.
- Firearms and chemicals, including household-cleaning products or insect sprays, should be stored out of reach in locked cabinets.

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