

DEALING WITH DIFFICULT BEHAVIORS

This may be a little tough to handle all at once. But we need to spend a bit of time talking about difficult behaviors you might see in a person who has Alzheimer's disease. Your love one may suddenly start acting hard to handle. Remember that he or she is not doing things to upset you on purpose. Alzheimer's disease damages the brain, so that, little by little, people who have Alzheimer's lose control over themselves and their actions.

Handling communications problems in stages 1, 2, and 3

Let me share how 3 families coped with the different stages of Alzheimer's in their loved one.

Stage 1 – the first stage

Miguel asked me to share this with you:

My mother forgot the names of people she knew for years. Neighbors, old friends she went to school with. Then she could not find the right words to express herself. She may have wanted sugar for her favorite morning ritual—a cup of fresh coffee. My mother might say, “I need the cup. Give me the cup.” Then she would pour so much sugar in her cup and spill it. And the telephone—well, my mama could not remember how to dial. This was hard to watch. My wife said we must go to a support group. The first few times, my wife went by herself, and then she talked me into going. I was so glad I went. I met other people who were dealing with the same things as our family.

What worked for Miguel's family:

Miguel said: We bought little packets of sugar and left them open on the table. Then we gave my mother a cup with a lid. We made sure that it had cooled off before we gave it to her so she wouldn't get burned. Also what also worked was going to support meetings to learn other good ideas.

Stage 2—the middle stage

Marisol has this to share:

My dear mother-in-law began to use sounds that others cannot understand. Sort of like this “ba ba la la na” She also was not able to understand simple instructions such as “Let's get your nightgown on for bed.” What was strange is that this happened almost overnight. I learned from my doctor that it could take a long time—so we were saddened to see this overnight change from understanding to little communication. We were blessed by one thing—my mother-in-law still expressed herself through laughing or crying. It helped us know what to do.”

What worked for Marisol's family:

We found that at this middle stage, my mother-in-law still had use of some of her senses. She reached out for the children to stroke their hair. She gave hugs. We played music and she loved that—smiled and moved her head from side to side.

Stage 3—the last stage

Jorge asked me to share this with you:

My Uncle Arturo became completely quiet and withdrawn. Once an outgoing person, he no longer responded to the outside world. Much of the time, he sat with his eyes closed. This quiet, withdrawn state eventually resulted in his death. I am sorry to speak so frankly, but it is important that you and your family understand the final result of Alzheimer's disease. This is important to learn even if your family member is only in the first stage of the disease.

What worked for Jorge's family:

Jorge said: We never yelled or lost our tempers. And we took Uncle Arturo along with us to family dinners and gatherings. We did not know how much he understood. We only knew how much we loved him and wanted him to continue to be part of our family activities.

Here are some ideas to help with communication problems:

- Realize you may not be able to reason with your loved one about a difficult behavior; he or she simply won't understand.
- Use a gentle tone. Don't yell at him or her, or give confusing orders.
- Use short phrases and simple orders, like "lift your arm please" or "come with me."
- Help your family member to change to other activities if he or she is doing something that is a problem.
- Use humor to help your family member stop doing a difficult behavior. Many people with Alzheimer's enjoy laughing, even if they don't understand what they are laughing about.

THE CASE OF MR. HERRERA. I would like to share the story of Mr. Herrera. Before his illness, Mr. Herrera had a great sense of humor. He loved to laugh. And even when he lost his ability to speak, he would laugh about things he thought were funny. His family found it helpful to laugh along with him, even if he could not understand them. Many happy hours passed this way, until Mr. Herrera entered the last stage of his Alzheimer's disease and he no longer was able to relate to the outside world. Not everyone with Alzheimer's will react to humor as Mr. Herrera did. However, laughter and conversation in pleasant tones can help keep some kind of communication going with the person who has Alzheimer's disease, even when the person you love has lost the ability to speak.

Some common difficult behaviors

There are certain behaviors that present special problems for families. You may find your family member with Alzheimer's:

Has trouble sleeping

Paces and wanders about the house

Hitting or biting

Acting out sexually—by touching themselves or saying things that are not appropriate

May show emotional or mental health problems.

Remember that you won't see all these behaviors at the same time or in any special order. Each person with Alzheimer's disease is different.

Problems with sleeping

You may have heard the term "sundowning" This is the most common sleep problem for people with Alzheimer's and it happens in the late afternoon and evening. This is what often happens. The person may have acted tired during the morning and afternoon.

But when the sun starts to go down, he or she may suddenly:

Become agitated

Pace around the room or through the house

Open and close drawers in their rooms or other part of the house

Act restless as the evening goes on, even when everyone is trying to go to sleep.

Here are some things you can do if you see signs of "sundowning"

- Try to get your loved one to go on a walk or do some easy exercises earlier in the day to help him or her feel tired and restful in the evening
- Make sure you do not offer tea or coffee with caffeine after 3:00 in the afternoon.
- Include healthy foods such as vegetables, fruits, rice, beans, and meat each day. Only give sleeping pills with the approval of your loved one's doctor.

What to do about pacing and wandering

Your loved one may pace and wander.

Pacing means restless walking from place-to-place, room-to-room inside the house. Wandering is when the person with Alzheimer's gets out of the house and gets lost. As you can imagine, for safety reasons, wandering is the most dangerous of the two behaviors

Why does a person with Alzheimer's pace and wander?

People with Alzheimer's may feel upset but not know why. They may need to go to the bathroom, may feel afraid if he or she is in an unfamiliar place or may be remembering old habits like going to work or shopping.

It is not important whether the person with Alzheimer's paces or wanders often or only once in a while. What is important is to take steps to prevent serious problems. Here's what I suggest :

- Put child protectors on the doors and locks to make sure your loved one can't open the doors to the street. You can buy these devices for a small amount of money at hardware stores.
- Buy sensors or alarms that sound if he or she tries to get out the doors.
- Disguise doors by hanging pictures on them, placing signs on them or putting curtains over them.
- Clear the hallways from objects so your loved one will not trip while pacing.

As much as possible, do things to keep your loved one calm. Try to get the person on a schedule for bathing, going to the bathroom or taking walks around the house or neighborhood. These routines may help with pacing, wandering, and agitation.

Controlling anger or violent behavior in your loved one

Sometimes people with Alzheimer's become very aggressive and even may try to hit or bite others. This can be a very hard for families. Remind yourself that it is the disease that causes aggression.

What causes this aggression?

1. Some people develop a mental health problem along with Alzheimer's. We'll talk about this a bit later.
2. Your family member may think friends and relatives they have known all their lives are strangers. Your loved one may be fearful.
3. Sometime people with Alzheimer's hallucinate, that is they see people who are not there. At times, you r loved one may not even recognize his or her own face in the mirror.
4. Sometimes physical pain that the person can't describe causes him or her to act out, kick, bite, or hit.
5. Some people can't handle noise or too much commotion. They need to have structure and routine in their lives to stay calm.

So, what can you do if your family member is acting aggressively?

- Try to limit contact with people who seem to upset the person with Alzheimer's.
- Rearrange the home or room as much as you can. Cover or remove

- mirrors if they seem to be upsetting your loved one.
- Draw the shades in the room or home if the person is upset by reflections in the window.
 - Try to find a doctor who is a specialist in Alzheimer's who may find a medical reason for the aggression. . For example, the person with Alzheimer's may need a new medicine, or may be having a bad reaction to the ones he or she is taking.

Speaking of medicines, there are some that can help control aggressive behaviors. Talk to the doctor about which ones will work best for your loved one.

Sexual Acting Out

As I have said earlier, as the Alzheimer's gets worse, you will notice your loved one a loses his or her ability to reason and to control their actions. Sometimes people with Alzheimer's take off their clothes and expose themselves or begin to act out in other sexual ways. He or she may think that strangers or even another family member is their spouse or companion, and may try to act out sexually with them. Not all people with Alzheimer's act out sexually, but some do.

It is important to realize that the sexual acting out happens because of the disease. It is not about morals. Of course, it is not appropriate for your loved one to take off their clothes or touch themselves in public and you want to help preserve their dignity. It is not appropriate for the person with Alzheimer's to be aggressive or sexual with a family member. Your loved one may not even realize what he or she is doing. They may miss the intimacy and sexual relationship they had with their spouse or companion, but do not know they are doing something wrong now.

Here is what other family members found helpful

- First try to find out why the behavior is happening. See if you can redirect the behavior. This means, try to get the person interested in doing something else, such as listening to music instead of touching himself.
- Talk to the doctor, nurse, or social worker for suggestions in handling the sexual behavior.
- Meet with a specialist in Alzheimer's if the acting out behavior does not stop.

The difficulty is that sexuality brings out strong feelings and reactions in all of us. But if you approach sexual acting out like any other difficult behavior in Alzheimer's, it will be easier for you to find solutions.

Emotional and Mental Health Problems

Mental illness can occur in people with Alzheimer's. You see, Alzheimer's impacts a person's brain in ways that bring on mental health symptoms.

Common mental health problems include:

Depression—being uncontrollably sad or withdrawn

Seeing or hearing things that are not there. This is called hallucination.

Thinking people are after them or out to get them. This is called paranoia.

The good news is that many of these problems can be treated with medicine. Although there are no medicines that cure Alzheimer's, there are several medicines that can help with depression, hallucinating, and fearful feelings. Of course we wish the problem would go away. Families tell me they have tried to pray the problem away. It is a good idea to have faith, but when there is a serious mental disease, it is also good to use medicines that may be very helpful.

You can take these 3 steps:

- First, bring the person with Alzheimer's to a psychiatrist, which is a doctor who can prescribe medicines for mental health problems. For best results, go to a geriatric psychiatrist. This person specializes in mental problems in older people.
- Next realize that mental health problems are not easily treated with home remedies, by talking to the person with Alzheimer's about the problem or by thinking that problems will just go away if you ignore them.
- Finally, so the medicines can work best, watch what happens to your loved one after taking medicine. See if you notice if he or she seems in a better mood or if his mental problems seem worse. Sometimes it takes a few tries with different psychiatric medicines before finding the one that works best for a person.

Once in a while the medicines may cause a person to be more forgetful or confused. This does not always happen ~~very often~~, but if it should, call the doctor right away to change the medicine.

Personal Care such as eating, bathing, and dressing.

Over time, your family member will need more and more help with their personal care. It is important to keep a balance between your loved one's independence and providing the personal care that he or she might need. He or she may need help with eating, bathing, grooming, dressing, and using the toilet. I know that this is not easy for the people who provide the care. Even with careful planning, it can be very hard work. Doing that work is a gift of love that you give to the person with Alzheimer's. .

Dressing

We make our decisions about what to wear based on what activities we are going to do (go to church, work, out to dinner, work in the yard). We pick our outfits to suit the weather. People with Alzheimer's often can't pick the right clothes. At times, even in the first stage of the disease they may forget how to dress. You may have to step in to offer help with choosing clothes, buttoning, lacing shoes and more.

- Place daytime clothes in the closet and pajamas in the dresser. This helps the person find the right clothes to wear.
- Wherever you can, replace buttons, zippers and belts with Velcro for easy dressing and undressing.
- Have fresh and clean clothes ready. Remember that we all feel better with clean and comfortable clothing—so will our loved one with Alzheimer's
- Bring along a sweater or coat for possible change in weather when you go out. People with Alzheimer's may not be able to say if they are starting to feel hot or cold.

Personal Hygiene –brushing teeth, combing hair, clipping nails and more

You may have to help your loved one brush her teeth because there are so many steps to remember—taking off the cap, squeezing the toothpaste, making sure it stays on the brush, brushing, then rinsing and spitting. Offer help if you see the person needs it.

Try these tips to make tooth brushing easier.

Here is Gloria's tip of the day: A regular toothbrush was just too hard for her Poppy to use. So, she bought sponge toothbrushes from a special medical catalogue that work great.

Here is Blanca's tip of the day: Her mother uses a non-spill glass with a lid, like the ones that young children use. No more broken glass and no more spills in the bathroom and she liked the bright color.

Even though the focus here has been on brushing teeth, there are many other parts of personal hygiene that also require attention, for example washing hands blowing the nose, trimming fingernails, etc. Men and women may need help with shaving and grooming hair. You may need to step in and provide help with all of these tasks. Talk to family members to figure out good ways to make these tasks easier for you and your loved one. It may be hard to imagine how difficult this simple act of brushing one's teeth or washing hands must be for a person with Alzheimer's. When you feel your own frustration rising, take a minute to calm down. Try to put yourself in the person's place. No—it is not easy. Yes—you are

very tired. Remind yourself what a loving thing you are doing for someone you love.

Make meal time smoother

People with Alzheimer's may still get great pleasure in eating and having meals with the family. In the early and middle stages of the disease, your loved one may be able to feed himself and sit at the table. As Alzheimer's gets worse, you may notice your loved one is not able to use a fork or spoon. Cutting food may not be possible. You may have to step in to cut foods, butter bread, and more. And sometimes your loved one may not remember to eat

To make mealtime go smoothly, try these hints:

- Try to eat at the same time, most days to set a routine.
- Plan meals and snacks throughout the day if your loved one has diabetes and must watch their blood sugar levels. You may have to prepare foods a special way for people with high cholesterol or food allergies.
- Offer water and liquids often throughout the day. Just don't give them too close to bedtime, or the person may wet his or her bed.
- When bedwetting becomes a regular problem, remember that there are adult diapers you can get. (We talk more about incontinence below)

Mealtimes are an important part of everybody's physical and emotional health. Mealtimes can be an important source of pleasure for your family member, even as his disease gets worse.

Bathing and Toileting

The everyday activities of bathing and toileting are so natural that we usually don't think about all the steps needed to do them. Bathing and toileting are also very personal acts. However, as Alzheimer's gets worse, your loved one will have less privacy in bathing and using the bathroom. At first, this can be very uncomfortable for you. Sons may feel very uncomfortable bathing their mothers. Daughters may be embarrassed helping wipe their loved one after bowel movements. Over time, families decide who is the best person to help the person with Alzheimer's with bathing and toileting.

It is important to note:

As Alzheimer's gets worse, bath time may get more difficult, the person with Alzheimer's may:

1. Become fearful--- remember that his vision may be changing and he may fear falling in the bathtub.
2. Be frightened of the sound of the water from the shower.
3. May simply refuse to bathe regularly. Or once in the tub or shower, may not want to get out. "

You can see that many different problems can come up around bathing and there are no easy solutions. However, caregivers report that planning ahead for bathing, sticking to a routine, and being loving but firm with the person with Alzheimer's can make the routine work over time.

Here's what I suggest for bathing:

- Find a set bath time and a routine BEFORE the Alzheimer's worsens.
- Get bathing and toileting things ready before you put the person in the tub.
- Keep a calm easy approach while you bathe your loved one.

Try these tips for toileting:

- Have soap, moist towels, and toilet paper ready to wipe the person
- Make sure the water is not too hot or too cold when helping the person wash her hands.
- To avoid accidents, go to the bathroom with your loved one about 15 to 20 minutes after she has a drink to encourage her to use the toilet. She might forget, or not be able to get the message from her body that she needs to use the toilet.

Bathing and toileting makes many demands on you, the caregiver, especially because these are very private behaviors. At the same time, helping the person with Alzheimer's properly care for his or her physical functions is a key part of good health and of preserving their dignity. .

Incontinence or lack of bladder and bowel control

There may be several reasons your loved one is not able to control urine or bowel movements. First check to make sure there is nothing wrong medically such as a bladder infection or stomach problems. Your loved one may not be able to tell you if something is wrong physically.

After the doctor checks for medical reasons, your loved one may still lose bowel and bladder control and accidents can happen.

In the early stages of the disease, accidents may occur because your loved one forgets to go to the bathroom or forgets to ask you for help.

In the middle stages and later stages, your loved one may lose control of the systems that make the bladder and bowels work. In short, the body might not be able to hold the urine in until the person gets to the toilet.

Try these suggestions that worked for other families:

- Set a regular bathroom schedule before the Alzheimer's worsens, and try as best as possible to keep to it.
- Learn the person with Alzheimer's non-verbal communication. Watch facial expressions or unzipping pants, which might tell when the person has to use the toilet.
- Put a picture of the toilet on the door to the bathroom to help make it easier to find the toilet.
- Put a commode, which is a portable toilet, by the side of the bed to help the person find the toilet at night, when they may be more confused. Commodes are also helpful for people who can't move around easily.
- Use adult diapers and clothes that are easy to open.
- Don't offer liquids before bedtime.

Safety for the people with Alzheimer's disease

When you think of safety for your loved one with Alzheimer's think both inside and outside the home.

Safety in the Home

You will need to make sure the home is safe even in the very early stages of Alzheimer's. As you'll recall with Dolores and her father-in-law from earlier sections, one of the early warning signs of Alzheimer's leaving food burning on the stove. A fire could happen in a matter of minutes. Other safety hazards in the home include forgetting to lock doors and windows at night, or getting locked out of the house.

There are many things you as the caregiver can do to safety-proof a home:

- 1) Make sure you take care of locks and keys.
- 2) Remove the stove knobs so the stove can't be turned on accidentally.
- 3) Cover doorknobs so that they cannot be opened without help. It takes only an instant for the person with Alzheimer's to be out the door and wandering down the street.
- 4) Add on new safety measures, as they are needed—like adding more locks, removing ladders etc.

Here are some steps you can take to make sure that your home is safe:

- 1) Go through the house looking for dangerous situations—shelves that can fall, cords that are loose. Make repairs as needed.
- 2) Buy and install home safety equipment such as window locks, childproof cabinet locks, and door locks.
- 3) Lower the hot water temperature so it will not burn your loved one.
- 4) Make sure garden tools and lawn equipment are stored safely.

- 5) Place all medicines out of reach.
- 6) Set up a home safety plan and make sure that family members, neighbors, and friends are aware of it. Be flexible so that you can change your plans as needed.

Safety Away from Home

It is harder to control your loved one's safety outside the home. Here's my advice for keeping your family member safe while he is away from his home:

- 1) First, make sure you bring enough diapers, water to drink and snacks when you leave the house.
- 2) Pack medicines.
- 3) Buckle your loved one in her seat belt and lock the doors. If you have a childproof safety lock on your doors and windows, make sure they are on.
- 4) Make fiestas and community events fun times. Do not leave the person with Alzheimer's alone. Ask other family members to help you watch the person so you can enjoy yourself too!
- 5) Find a quiet corner or private room for your loved one to rest if you find there is too much noise and stimulation when you visit friends or go to events.

You may want to enroll your loved one as a patient in the *Safe Return* program sponsored by the Alzheimer's Association.

How the Safe Return Program works:

- First you have to enroll your family member and there is an enrollment fee. Call *Safe Return* at 1 800 --- -----
- The person with Alzheimer's gets an identification bracelet, or necklace, and labels for clothing that have his name, address, telephone number, and the 1-800 number of the Safe Return Program on them.
- If the person with Alzheimer's wanders off, police or anyone who finds him, will be able to contact you or the 1-800 number on his bracelet or clothing. While the Safe Return Program can't keep your loved one from wandering, the program has an almost perfect record in helping return people with Alzheimer's to their families when they have wandered.