

*Caring for Someone with
Alzheimer's...Real World
Strategies that Work!*

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Introduction

Caregiving for someone with Alzheimer's is one of the most difficult jobs in the world. In addition to making sure that your loved one's daily needs are met, you are also faced with the fact that your relationship with this person is no longer what it once was. Plus, you are trying to maintain some sort of life of your own.

Many caregiving guides out there give very technical and clinical information to try to enable caregivers do a better job. In my work with caregivers and the people they care for, I have found that what they need is practical information and useful suggestions to make the everyday things of life easier: How can I get Mom to take a bath? What do I do when Dad won't sit down and eat? What do I do when my husband becomes agitated and upset? These are the things that, when faced everyday, lead to caregiving burnout. Caregiver burnout is what leads to the need to place your loved one in a nursing home.

My hope is that this report gives caregivers practical information and ideas to help make their job easier. As you read through this information, you might see a similarity in my suggestions and how you might care for a child. I never approach the care of someone with Alzheimer's in a childish manner, but there are some childlike qualities to the Alzheimer's patient and, therefore, in some of the approaches to caring for them. I hope you find the information helpful and useful.

Picking your Fights

When I was directing an adult day care center, I worked with a lovely woman I will call Sue. Sue had Alzheimer's and lived with her daughter and son-in-law. She attended the center five days a week while her daughter Mary worked. At about 3:00 everyday, Sue would begin letting everyone that she had to leave because she thought her mother was expecting her home for supper. Of course her mother had been dead for years, but Sue would continue talking about it until her daughter Mary came to pick her up. Then Sue would begin telling her daughter that she needed to get home to her mother for supper.

Everyday Sue and Mary would leave the center with her daughter Mary telling Sue, in a loud voice, "I told your yesterday, and everyday before, that you live with me. Your mother is dead and is not expecting you home for supper."

Does Sue's behavior sound familiar: repetitive questions, stories or demands that you make you want to scream? It's so frustrating to deal with. It may help if you remember that each time that question is asked, or story is told, it's like it's the first time for the person you are caring for. When you are tired, it's easy to imagine that they are just doing it to drive you nuts! However, it is important for you to remember that no behavior, even physically aggressive behavior, is rational and intended to frustrate or hurt you.

When Sue Mary would leave the center, you could see their frustration level rising as they headed to the car.

Later, Mary would take to the staff about how difficult evenings were at home with Sue. We spent some time with Mary letting her work through the emotions she was feeling: the frustration and anger at her mother as well as the sadness she was feeling about her mother's decline.

I gave Mary a tool to use every time she felt that frustration and anger at her mother's behavior. I told her to ask herself: Is this situation worth an argument with her mother? In other words . . .

"Is this really a problem . . . or is it just a problem for me?"

Does it really matter that Sue thinks she is going home to her mother to have supper? Is it worth arguing and upsetting her and everyone else at home?

Sometimes a situation did call for disagreeing with Sue's demands . . . like when she wanted to leave the house and walk home at 10:00 at night. In general, however, very few situations really justify the need to start World War III.

It was also helpful once Mary realized that Sue thought she was perfectly rational and she thought that Mary was the crazy one!

Perception is reality. When caring for someone with Alzheimer's remember that you are dealing with more than one reality: yours and your loved one's

When Mary began to use the intervention I suggested, things started going much smoother at home. It all came about because of a simple question Mary began to ask herself: "Is this really a problem . . . or is it just a problem for me?"

Consistency: One of your best tools

One of the most important things you can do to help relieve boredom and anxiety is to keep your loved one on a regimented daily schedule. If you keep the same schedule every day, your loved one will be more likely to sleep at night, will remain continent longer, and will also be less agitated. Try to have your loved one wake, eat, nap, and go to bed at the same time every day.

Activities to stimulate the abilities they still have are also important. As the disease progresses it can be difficult to do this on your own. That's why I recommend having your loved one attend an adult day care program, if there is one in your area, at least a few days a week. This will give your loved one a schedule and it will give you a break. While it's not always possible, do your best to keep your loved one a schedule with short intervals of activity. Here is an example of a daily schedule you might want to try for you and your loved one. Remember that everyone is difficult, so adjust it to fit your situation.

Sample Daily Schedule

- 7:00 Wake and assist with toileting and dressing
- 8:00 Have your loved one assist in preparing, serving, and eating breakfast
- 9:00 Assist with toileting
- 9:30 Read the paper together and have coffee
- 10:00 Quiet time (give them a magazine, watch TV, etc.)
- 10:30 Activity (Go for a walk, go grocery shopping, do a craft, etc.)
- 11:30 Assist with toileting
- 12:00 Have your loved one assist in preparing, serving, and eating lunch
- 1:00 Assist with toileting
- 1:30 Nap time
- 2:30 Wake from nap and assist with toileting
- 3:00 Activity (give them project, do a craft, etc.)
- 3:30 Quiet time
- 4:00 Assist with toileting
- 4:30 Activity (go for another walk, read another section of the paper)
- 5:30 Have your loved one assist in preparing, serving and eating supper
- 6:30 Quiet time
- 7:00 Assist with toileting, bathing and preparing for bed
- 8:00 Soothing activity (listen to music, read together, etc.)
- 9:00 Assist in going to bed

This schedule may seem very unrealistic to you, and it might be! Just keep in mind:

Don't let your loved one sit or sleep all day, especially if they are up and wandering at night. A safety note: if he or she wanders, and could get out of the house, pin a piece of paper to him or her every morning with his/her name, address, phone number and your name on it. Better to be safe than sorry!

Do things in short time periods. Someone with Alzheimer's usually has difficulty concentrating on one thing for a very long period of time.

Plan activities: these can be anything that interests your loved one and uses the abilities they still have left. For instance, if your loved one worked in an office, create office-type projects for them. This could be as simple as sorting or rearranging all the junk mail you receive. If they loved cooking, set up a cooking activity for them, even if it is as simple as spooning cookie dough or stirring Jell-O. You get the idea.

If you encourage and assist them in toileting regularly, it will enable them to remain continent longer.

Use the quiet time to do the things you need to do.

Daily Activities: Helping them to go smoothly

Eating, bathing, dressing, toileting: These are the things that can be most frustrating when caring for someone with Alzheimer's. Here are some practical solutions to common problems that arise in this area.

Eating.

Why is such a struggle at times? There are a couple of reasons that may not be evident. The first is that, as we age, our ability to taste decreases. Food becomes bland and needs more spice to make it taste good.

I was having a casual conversation with a friend of mine about our grandmothers, and the wonderful things only they could cook, when this topic came up. She said, "Well, that explains why we have arguments every holiday about how much salt she is putting in her recipes." As she's gotten older, she needs a lot more salt to make her food taste the way she always liked it.

You might want to try adding a little more spice to the food if your loved one is stating that he or she does not like it. Be sure to follow any dietary instructions the physician gives you. Remember, you might think it is too spicy, peppery, or salty, but it might be just right to him or her.

Presentation of food can be important, also. Individuals with Alzheimer's often develop perceptual difficulties. As the disease progresses, their vision may become distorted. I've watched clients walk across a tile floor and step over a dark tile in the pattern because they think it's a hole. I have also used this to my advantage when I did not want my clients at the adult day care program to go through an emergency exit door. I painted the door jamb and the door the same color as the walls, and I also secured shelves to the door to make it look like a bookcase. Problem solved!

Because of this same difficulty in perception, it is helpful, when serving food, to have the plate a different color from the table, and to serve food that is not the same color as the plate.

If you have a natural wood table, use a navy blue plate and the food will stand out on top of it. Don't, for example, serve chicken and mashed potatoes on a white plate while you eat on a white formica table.

In addition, be sure you are offering utensils that are easy to grasp. If your loved one develops difficulty grasping regular utensils, medical supply stores often have utensils especially made of people who have lost motor skills.

If your loved one paces and won't sit down for a meal, then let them take the meal with them. Prepare finger foods that he or she can eat while pacing (i.e. finger sandwiches, nutritional supplements in a cup with a spill-proof lid, nutritional supplement bars.) The important thing

is that he or she is getting enough nutritious calories to maintain good health, not that he or she meets etiquette standards while doing it.

Try to keep your loved one away from caffeine or sugar. Caffeine can decrease one's appetite and can wreak havoc with their sleep schedule. Sugar can increase agitation and offer a feeling of being full without consuming any valuable calories.

One of the best things you can do is to encourage your loved one to drink water or other appropriate beverages throughout the day to keep them adequately hydrated. Hydration can affect one's skin greatly. If someone is not adequately hydrated, their becomes thin and dry like paper and can tear very easily. Poor hydration can also contribute to the development of bed-sores. Adequate hydration will also aid in reducing constipation.

Bathing and Hygiene

One of the biggest complaints I hear from caregivers is that it's impossible to get their loved one to take a bath or perform other daily hygiene activities. Again, this is not usually a conscious attempt to make you crazy. There are a number of reasons why someone with Alzheimer's is reluctant to take a bath. Unfortunately, they are unable to express those reasons. Before bathing your loved one, be sure you have the appropriate equipment: hand/grab rails, non-slip tub mat, and a shower stool.

Let's go back to the perception problem. I have seen people with Alzheimer's unable to understand why they can't walk through a glass door, or figure out how to open it. The same perceptual problems occur with water. Many times they don't perceive water the same way you and I do. Most tubs are white and filled with clear water. It's frightening to step over the side of a tub into water, which they can't see. You may want to try adding bubbles or bath salts that color the water. This might help your loved one understand better what is happening. Also, it seems to be less frightening to introduce the water slowly starting from the feet and working upward. It is too shocking to their system to sit them down directly in the water.

Next, be sure to stick to a routine when bathing. Try to schedule bath time at the same time each day. Make the process a ritual where they assist in disrobing, filling the tub, and washing. Take it slow and guide them gently. If you try to rush them through the process, chances are both you and your loved one are going to be quite agitated and upset afterward.

Be sure that the bathroom is very warm before you begin the bathing process. As we age, especially if we have circulatory problems, we get cold easier and we want our environment warmer than we did when we were younger. Most people with Alzheimer's are unable to tell you that they are cold, so be sure to keep them warm to begin with, rather than letting them chill.

When it comes to other forms of hygiene, you might have to improvise. If oral hygiene is a problem, you might want to try an alternative to brushing. Many medical supply stores have oral swabs for cleaning the mouth. They usually have a cleaning substance, such as glycol-

erin, on the swab to aid in cleaning the mouth and teeth.

Throughout the day, offer your loved one a warm wash cloth to clean his/her hands and face. This will assist in removing dirt and food and it is quite soothing to them.

Dressing

Comfortable and safe: that's what I recommend when assisting your loved one in dressing. Many people with Alzheimer's want to put on layer after layer of clothing. This might be because they are cold, or they don't remember that they are already wearing a sweater, or it might simply be the kind of repetitive hoarding or gathering of items that many Alzheimer's patients exhibit.

Again, pick your fights. Is it really so terrible that Mom wants to wear 3 shirts? If Mom is comfortable with two shirts and no bra, is that worth the struggle?

Shoes can be a problem. Make sure the shoes are easy to get on and off (Hush Puppies work well) and that they have a non-skid sole so that they provide traction. This especially important when you start to see a change in your loved one's walking (i.e. they lean forward when they walk, they shuffle their feet, etc.) I do not recommend shoes with shoe strings because they are more difficult to put on and remove. The shoestrings also provide a hazard for falling if they become untied.

Outings

Before you plan an outing with your loved one, ask:

- * If it is necessary?
- * What is the best time of day to go?
- * What will you need to have with you in case of problems or an emergency?

I had the daughter of a client tell me how embarrassed she was at church because Mom wanted to wander during the service. Plus Mom talked loudly all the way through. I asked her why she was taking Mom to church to begin with, and she replied, "Mom has always gone to church on Sunday."

I asked her if she thought Mom knew she was at church, and if she was getting anything out of it. She said she didn't think so. I suggested that perhaps church could be something the daughter does for herself, and that she let Mom stay home with other family members.

It is so difficult to see such a decline in someone you love, but I don't think "we've always done it this way" is a good enough reason to continue to do something that is not adding value to your loved one's life. Taking your loved one out of the house can often times cause more anxiety and frustration than pleasure. When he or she is out of familiar surroundings, it can cause fear and increased agitation due to too much stimulation.

Of course, many outings such as doctor's appointments are necessary. I recommend that you try to schedule such appointments at the time of day when you know your loved one is at his or her best. If your loved one becomes anxious in the late afternoons, try to schedule the appointment for mid-mornings so that you can return home, eat lunch, and then he or she can nap. Take plenty of time getting there and leave enough time so that you aren't hurrying. Rushing causes agitation.

Be sure to take those items with you that will aid in calming your loved one should he or she become upset while out. This can include food, pictures he or she likes to look at, familiar items from home, or a favorite afghan. If it's a medical appointment, have on hand all the important information and items such as insurance cards, medications, medical history, and the names of the other physicians caring for him or her.

Physician Visit Notes and Medications

It is very difficult to try to remember everything that's discussed at a doctor visit. If you are dealing with more than one physician, it is even more difficult to keep it all straight. Too often, we take a passive approach to healthcare and "go with the flow" of what physicians and other health care providers tell us.

A better approach is to be more active in your loved one's medical care. The first step to doing that is to have a record of his or her medical care. Create a place where you can keep notes of doctor's appointments, what was discussed and any instructions or changes in medications. You can refer back to these notes when working with other health care professionals to make sure that there is continuity in the care he or she is receiving. Don't be afraid to ask questions if you don't understand something a physician says, or why the doctor is prescribing a medication. You are the customer in the business of health care and you deserve good customer service.

It is also vital to keep track of your loved one's medications. Many times, the Alzheimer's patient is being treated for multiple conditions. Keep an up-to-date listing of the medications he or she is on and the instructions on dosage and administration. You might need to share this information with other physicians or caregivers, and if there is ever an emergency, you will have the information at your fingertips. Remember, write in pencil as there could be changes in dosages or administration.

Caregiver Relief

You have to take care of yourself.

Neglecting your needs does not help your loved one. Here are a few suggestions to help you and the others providing care come relief.

* When your family and friends offer to help out, accept their offer. Let them help out for a few hours a week while you go shopping, get your hair done, play golf, or just go sit

somewhere quiet where you can find some peace.

- * If you have the financial means, find a private duty home health care agency to provide a sitter or an aide on a regular basis.

- * Enroll your loved one in an adult day care program in your area. The cost can range from \$30 to \$100 or more per day depending on where you live. An Alzheimer's specific program would be preferable, but most centers can provide excellent day care to adults with all sorts of physical or cognitive disabilities. This is also a great assistance to working caregivers.

- * Don't think everything has to be perfect. Perfection is an illusion. We never really reach it! The house does not have to be spotless and the meals don't to look like Martha Stewart prepared them. Take care of the important things, learn to say no when you just can't do anything else, and make sure you are taking care of yourself.

- * Provide written instructions for your relief caregiver that gives helpful information so they can do the best possible job while you get a break.

- * Attend Alzheimer's caregiver support groups. Your local chapter of the Alzheimer's Association can provide you a list of meetings in your area or you can contact the social service department of your local hospital for a referral.

When is it time to look at Nursing Home Care

There's no perfect formula to determine this. You need to consider the big picture, not just how your loved one is doing. You also need to consider how you're doing. Here are a few things to look at when you are facing this decision.

- * Is your loved one becoming too physically frail to manage safely at home?

- * Is your loved one agitated and dangerous to you or others?

- * Are you becoming ill or physically exhausted?

- * Does your loved one's physician recommend that you consider finding a nursing facility?

- * Is caregiving for your loved one causing too much stress on the rest of the family?

- * Is your loved one causing too much stress on the rest of the family?

You will know when the time comes. Trust your instincts. Focus on what is best for your loved one with Alzheimer's, as well as for the entire family. Placing someone you love in a nursing facility is no one's first choice for care, however there are good facilities out there.

When that time comes, just remember, you did the best you could, for as long as you could. Who could ask more than that.