



## Alzheimer's Association Tuesday Talks

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*Personal Care Battles*

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Let me first take a minute to introduce myself and today's topic. My name is Laura McKay and I am a registered nurse working for Home Instead Senior Care in Fairfax County, Virginia. Home Instead is a Nationwide home care agency that specializes in companionship, respite care and personal care services for aging seniors. The topic today that I've been asked to present is Personal Care Battles. With about half of our clients experiencing some level of dementia, our staff of professional caregivers face these "Personal Care Battles" on a regular basis.

Exactly what do I mean by "Personal Care Battles"? Personal Care refers to assistance needed with normal activities of daily living such as eating, bathing, dressing, and toileting or incontinence care. The "Personal Care Battle" occurs when the caregiver's agenda for meeting the client's personal needs conflicts with the perceptions, wishes and desires of the person with dementia.

Here are a few examples from real life scenarios:

- (1) Mom always had a healthy appetite and loved pasta and fresh fruits and vegetables. Since the Alzheimer's symptoms progressed, she only picks at food, refuses foods that she once loved, and some days she doesn't even seem to remember how to use her utensils. Getting her to eat good meals is a daily battle.
- (2) Dad used to shower every morning as soon as he woke up. Now, getting him to shower and change his clothes is a daily battle. When asked to take a shower he says "I showered yesterday" or "I'll take one tonight" or "I don't feel like it". When I am able to get him into the shower, he insists he doesn't need any help but will sometimes come out of the shower without using soap or with the shampoo still in his hair. How did something so basic as bathing becomes such a struggle?
- (3) My client with Alzheimer's has been having frequent bladder accidents. I sometimes see her becoming agitated or pulling at her clothes but when I ask her if she has to go to the bathroom she says "no". When she has an accident, which is becoming more and more often, she is embarrassed or angry if confronted. What can I do?

What can we as caregivers do to help prevent or reduce the stress of the daily personal care battles? The first thing we must do is manage our own expectations. We must realize that the dementia is affecting the client's abilities, THEY cannot control it and WE cannot control it. While we may want our loved one to shower regularly or eat 3 nutritious meals, there are days when despite our best efforts we cannot make this happen. Keeping in mind the importance of good nutrition and good hygiene we need to use patience, persistence and creativity to avoid or reduce the personal care struggles.

In the next 20 minutes, I'm going to discuss some tips and techniques that caregivers can utilize in helping navigate through the difficult waters of personal care. These tips and techniques will work in both the home and facility environments and can be used by professional caregivers and loved ones of people with dementia alike. Remember, there is no "magic bullet" that works for everyone, so be patient and creative to try to find what works for you.

### **Eating**

Adequate nutrition and hydration is extremely important for seniors, but as dementia progresses, eating can become very compromised. Individuals who once had great appetites and ate a variety of foods may become very picky and difficult at mealtime. Tastes and appetite may change dramatically from day to day or meal to meal.

Here are some tips and examples to make mealtime more successful:

- Be very consistent with meal times. Eat at the same times each day. Select meal times that are in keeping with routines that were in place prior to onset of dementia. If she always liked a cup of coffee before a light breakfast, try to keep this routine. If dinner was at 6pm in the dining room, try to keep this routine.
- Keep the table area very simple: Use plain, light colored plates that foods will stand out on. Avoid busy patterned table cloths and patterned napkins and placemats. Keep extra dishes, condiments, and sauce containers off the table. Bold colors or patterns and additional items on the table can be very confusing and distracting. I once worked with a client who had a difficult time focusing on eating. She picked at the weave of her placemat throughout the meal and had to be redirected over and over to eat her food. At the next meal, when the placemat was removed and replaced with a plain white plastic one, she was able to eat much better.
- Try soothing music and keep conversation light with no background noise or background conversations going on. You may find that family get togethers or parties are particularly hard times for loved ones with dementia to eat. Feed them their meal before the party or afterward in a quiet place and let them snack on finger foods during the party.
- If she can no longer cut up foods or put on sauces, seasoning or condiments, do this before bringing their plate to the table. These activities can distract or confuse the person with dementia causing them to not eat well.
- Encourage him to do as much as he can himself. Use simple verbal cues, breaking tasks down in to simple steps. Instead of "Eat your dinner", say: "Pick up your fork, take a piece of chicken, chew, pick up your milk. Give these cues one at a time and don't give the next instruction until the first is complete.
- As dementia progresses, she may not be able to use utensils, even with prompting. Feed her the foods that require utensils and prompt her to feed herself the finger foods.

- If he or she has trouble sitting down to eat, give finger foods such as carrots, raisins, grapes or dry cereal that can be picked up and eaten on the go or while watching TV.
- foods that combine solids and liquids like stew, chunky soups or cereal with milk may be confusing for people with dementia because they don't know whether to swallow or chew. If this is the case, try minimizing the liquids in these foods and having them eat it with a spoon.
- Never force feed, yell, or let your frustration show – this will only make the battle worse. If nothing seems to work and you are getting frustrated, remove the client from the meal area, take a break from the meal and try the meal time again a little while later.
- If your loved one is absolutely refusing to eat any foods at a meal, focus on liquids to keep her hydrated. Boost, Ensure or Carnation Instant Breakfast are great nutritional supplements. Pureed foods may be tolerated better than regular foods if she is having difficulty with chewing. Protein powder can be added to pureed foods to boost calories. Try different methods of delivery like straws, sippy cups (remove the valves for easier flow). Spoon feeding or slow syringe feeding may be necessary in the final stage of dementia. Check the mouth after eating to make sure she is not pocketing or holding food in the mouth which she could choke on later. Make sure she takes plenty of liquid to wash the meal down.
- Unfortunately, there is no one trick that works for everyone. Each person with dementia is different and their responses to eating may vary from day to day or meal to meal. I've found that some do better with the same foods served every day for meals. One client of ours eats beautifully when served the same exact breakfast every day (raisin bran with cut up banana, half a peanut butter sandwich on whole wheat bread, water, and her pills crushed in applesauce). The foods are provided one by one in the same order each day at the same time. If given a variation of routine or foods, she becomes agitated and does not eat well. Another client we care for has rapid changes in taste, spitting out a food one day that she devoured the day before. The caregiver must have plenty of variety of foods available to try to find one that entices the client to eat.

### **Dressing**

Dressing each day and undressing at night is something we do almost mechanically. Dressing and picking out clothes is a way of expressing oneself and adapting to our seasons and weather conditions. Dementia can make dressing and undressing a twice daily stressor for caregivers.

Some common battles that center around dressing are:

- Not wanting to change clothes (wanting to stay in the same clothes day and night)
- Putting on multiple layers of clothing, sometimes in the wrong order.

I once worked with a client on a dementia unit in a skilled nursing facility who if left alone in her room in the mornings would try to put on every article of clothing in her

closet and would come out of her room wearing 4 or 5 outfits at once, sometimes with her bathrobe on top!

-Taking off or trying to take off clothing in public

Try these tips to avoid dressing battles

- Keep clothing comfortable, soft and simple to put on (slip on shoes, elastic pants or skirt, pull over tops, thigh high hose or knee socks rather than pantyhose)
- Use simple, straight forward step-by step instructions when assisting a client to dress. Instead of “now put on your shirt”, try “here is your shirt. Lets put it over your head, now put your hand in the sleeve, etc)
- If he or she is removing clothes in public, try clothes that fit snugly and zip or button in the back.
- To prevent putting on of multiple outfits at once, pair down the wardrobe or set up clothing ahead of time with items to be put on first, like underwear, on the top of the pile.
- If he doesn’t want to take off or change clothes. Try a few of these tips:
  - Do not ask “Do you want to change your clothes?”. The answer will be some version of “no”. Instead try, “It’s time to change clothes, Come with me and I’ll help you”.
  - Make sure room is warm, quiet with no distractions such as TV or radio voices which may distract or frighten him.
  - Be flexible. If he is resistant to changing clothes, have him change clothes when he or she is at their most alert and receptive, even if that is not 1<sup>st</sup> thing in the morning or right before sleeping.
  - Once, you’ve found a time that works, keep the routine the same. Assist the client to changes clothes in the same place at the same times each day.
  - Get several identical or very similar outfits.
  - Sometimes when all else fails, you might have to use what we in healthcare call the “therapeutic fib” to encourage cooperation. These therapeutic fibs should only be used with individuals with very poor short term memory. An example of this would be telling a client who has refused to bathe and get out of her housecoat all day that you are making a very special dinner tonight and want her to get washed and “dressed up” for it. Or telling your father who has dementia that you’d like to see him wearing the new shirt you got him for Christmas.
  - Finally, Manage your expectations: Is it critical that your mother changes in to nightgown every night if the jogging suit she wore during the daytime is clean?

### **Toileting**

As their dementia progresses, people with Alzheimer’s begin to experience a greater difficulty with continence and toileting hygiene. Let’s discuss some toileting tips:

- Do not ask “do you have to go to the bathroom?” Instead, say “The bathroom is over there, I’ll walk with you”.
- Look for signs that the client has to go to the bathroom. Some people will tug on clothes, wander, or open doors as if looking for the bathroom.
- Make sure that clothes are easy to remove in case of sudden urges.

- Walk client to the bathroom every 3-4 hours while awake. Keep a written log of times of urination and bowel movements. Look for patterns and try to take client to the bathroom at these times each day.
- Having the right equipment and supplies in the home may make toileting easier. Some of these items include:
  - Raised toilet seats with handles
  - A bedside commode
  - Urinals for men
  - Poise pads, pull up briefs, or adult diapers
  - An air tight diaper pail that is easy to open
  - Hypo-allergenic, fragrance free baby wipes or flushable wipes (you can warm them by putting them briefly under warm water or for a few seconds in the microwave)

Remember, it can be very challenging to teach a person with dementia how to do something new. Something as simple as using a bedside commode or urinal when the client is used to going into the bathroom to urinate, may confuse or agitate them. Be patient, calm and go through instructions step by step. If they can't adjust to it, give it up and try again later.

### **Bathing**

Bathing can be the biggest personal care challenges for caregivers of people with dementia. Fear of water, pain or discomfort getting into shower or tub, fear of falling when getting in and out of the shower, fear of nudity, inability to remember how to bathe, embarrassment over needing assistance with showering may all factor into the resistance that people with dementia have when approaching this task.

Nevertheless, maintaining good hygiene is very important for seniors, especially if they are incontinent. Seniors skin is thin and does not retain moisture well, so daily bathing is typically not necessary, if they are continent. However, it is essential to remove fecal or urine waste completely from the skin to prevent skin breakdown, soars, odors, and infections. Good hygiene protects skin integrity and prevents pressure sores and prevents infections and fungal growths on skin. So what can we do when a loved one or client is absolutely resistant to bathing?

- First, watch your approach. Don't ask "Do you want to take your shower now?" Instead try, it's Monday and time for you to take your shower. Come with me.
- Again, keep the routine simple. Stick to the same bathing times or days and the same routine.
- Prepare all needed items like towels, shampoo, and bathrobe ahead of time before you bring the client into the bathroom. A flurry of activity before the shower may increase anxiety and agitation.
- If the client needs prompting, keep instructions simple and step by step
- To reduce embarrassment try distraction techniques like singing together, light joking or conversation. I have one caregiver who sings with her client in the

shower and this distraction has made a world of difference. Where she used to fight and resist now she really enjoys it!

- If client is refusing, getting angry anxious or agitated when shower or bathing is mentioned, drop it and try a different approach a little later You may find that you get a completely different response.
- If a shower meets total resistance, try alternatives like washing with a mild soap and washcloth in the bathroom. Try cleaning one part at a time removing clothing and replacing with clean clothing with each part washed.
- If washing hair meets resistance, try washing hair in the kitchen sink, a dry shampoo or scheduling weekly appointments at the beauty parlor for a wash and set hairdo.
- If all else fails a therapeutic fib might help. We have a client who adamantly refuses to shower but when told that her family is coming to take her out to dinner, she usually reluctantly agrees. Since she does not remember this promise a few minutes later, it does no harm to use this bait to get her to take her shower.
- Some equipment and supplies that might help make shower easier include:
  - Shower bench – the type with back and sides tend to make clients with dementia feel more secure.
  - A handheld shower to control flow of water
  - Bath in a bag products. These products are packages of 8-12 personal cleansing wipes that are heated in the microwave and used in place of a sponge bath. The large towelettes have no rinse soap, vitamin E and Aloe to clean and protect skin. They can be found in medical supply stores and pharmacies.
  - No rinse shampoo comes in a variety of types

Most clients with Alzheimer's experience some degree of resistance to personal care tasks. Hopefully some of these tips may work and with patience, persistence and creativity you will be able to lessen the stress of these battles. However, I am in no way promising an end to the day to day struggles of personal care. There are going to be days when despite your very best efforts and every trick in the book, you just can't get Mom to clean herself well or let you help or you just can't get Dad to eat anything but cookies for dinner. You just have to accept this, lower your expectations a bit and remember that tomorrow is another day.

It is absolutely paramount that you take care of yourself too! To avoid caregiver burnout make sure you are getting some time for yourself. If stress is getting to you, take a nap, take a shower or bath, exercise, do a crossword puzzle, read a magazine or book, participate in a support group or talk with supportive family or friends. Don't think that you have to do it all by yourself. Let family, friends, an adult daycare or a professional caregiver look after your loved one to give you that much needed time away. Try to schedule this time for yourself on a regular basis.

When looking for a professional caregiver for respite services look for specific training and experience in Alzheimer's care. When using an agency, make sure to utilize one that provides continuing education for its caregivers and does a comprehensive criminal background check and drug testing.

For more tips, support and assistance for caregivers, I would recommend the following resources:

The Alzheimer's Association [www.alz.org](http://www.alz.org)

The Alzheimer's Playbook [www.alzheimersplaybook.com](http://www.alzheimersplaybook.com). This is a wonderful guide through the stages of Alzheimer's disease written by coach Frank Broyles former coach of the University of Arkansas Razorbacks.

Caregiverstress.com – This is an on-line resource for family caregivers with resources and information on topics such as avoiding caregiver stress, caring for yourself when caring for others, and a wonderful stress assessment tool.

I want to conclude with a poem written about Alzheimer's by an unknown poet. I think its message resonates with all of us:

Do not ask me to remember.  
Don't try to make me understand.  
Let me rest and know you're with me.  
Kiss my cheek and hold my hand.

I'm confused beyond your concept.  
I am sad and sick and lost.  
All I know is that I need you  
To be with me at all cost.

Do not lose you patience with me.  
Do not scold or curse or cry.  
I can't help the way I'm acting,  
Can't be different 'though I try.

Just remember that I need you,  
That the best of me is gone.  
Please don't fail to stand beside me,  
Love me 'till my life is done.

Now with the remaining time I can take any questions that you may have.