

In the Case of Interests, Hobbies & Activity Preferences, an Alzheimer's Diagnosis Means Nothing

Unfortunately, many times caregivers feel that an Alzheimer's diagnosis means everything when it comes to activities, but it doesn't. Certainly the way the afflicted individuals engage in these activities may change for any number of reasons (medication side effects, lack of sleep, difficulty with language or motor skills, etc.), but the person in your care has not lost all of his or her history or identity. If Bonnie enjoyed gardening all her life, why would a diagnosis change that? If Clark loved watching the World Series and has fond memories of doing so every year since the age of 5, why should he stop?

Alzheimer's Is About Adaptation

Those living with cognitive impairments — and their caregivers — are constantly adapting to the changes wrought by the disease. Sometimes, those adaptations are subtly applied and integrated into the daily routine; other times, a drastic adjustment is required of both parties. Nevertheless, adaptation is a regular, recurring part of a life with Alzheimer's.

When planning for and providing meaningful, stimulating activities for those with Alzheimer's and related dementias, consult the individual's personal history for clues about favorite pastimes. A Life Story Questionnaire completed by a family member or friend (see handout) can be a valuable tool, and this information can be used as the foundation for a personalized activities and one-on-one interactions. If and when it is necessary, adapt these activities to fit within the framework of the individual's abilities. Maybe Joanie used to walk every day, but now needs a secure environment because the risk of wandering is too great. Could she take a walk around the neighborhood accompanied by a caregiver or would it increase her agitation? Maybe outside time in a secured environment would meet some of her needs. Find a respectful balance that promotes her independence while ensuring her safety.

If Bob took beautiful photographs of the birds, there is no need to let the Alzheimer's diagnosis take that away too. You may be able to help him use a point and shoot digital camera to take pictures and then upload and print the photos for him. Don't change a thing unless you have to.

Unfortunately, this method is not 100 percent foolproof. Sometimes, the whims of Alzheimer's disease prevail, wreaking havoc on an individual's personality/mood, which might mean they lose interest in things that they had enjoyed previously. If the safety of the individual is at risk by participating in certain hobbies, you may need to discontinue or alter them accordingly. For example, safety, physical and mental constraints may keep a former woodworker from being able to use the tools of his hobby, but there may be ways he can still enjoy the tactile feel of different woods and finishes. Do be sensitive to a person's frustration as they lose the ability to do past activities and work to find new avenues for them to explore.

Setting the tone of an activity can be hard, so the most important thing in a memory care community is for all employees is to **KNOW THEIR RESIDENTS**. Who they are now and who they were in the past.

Here again, the Life Story Questionnaire is invaluable by allowing a look into the person's life that they may not be able to tell us about. "John, tell me about living in Cincinnati and working at your Dad's Italian restaurant." Or "Patricia, tell me about when you would go dancing."

Having this information will open up opportunities for both the person running the activity and for the person who is participating. On the surface the person that you are interacting with may not bring up this part of their lives, but if you bring it up and you start talking about it, it might be the spark they needed to remember certain parts of their past. Too often a person is given no identity beyond their Alzheimer's diagnosis, yet there is so much more to them than their disease.

It's also important to keep in mind what the residents will see all day. Having living things — be it live plants, fish tanks or therapy animals — helps foster a sense of life and enjoyment. These things that can be turned into activities as well by having the person help water the plants or feed the fish or stroke the bunny. Helping is a meaningful activity and lets them know that they are still contributing.

Patience

When it comes to working with people who have Alzheimer's, one of the most important things you can equip yourself with is **PATIENCE**. When it comes to daily interactions, it is important to be aware of the nature of Alzheimer's disease, how it affects the brain. Short-term memory is affected most severely, especially in the earlier stages. So the person you are interacting with may have no memory of something that just happened. This means that you might find yourself repeating something that you just told the resident.

An example is the person who asks the same questions throughout the day. "Sir, what time is it?" "3:46" Time passes "Sir, what time is it?" "3:47." He just doesn't remember. When someone with dementia asks you for the twentieth time what time it is or how many kids you have, to them, it is as if they are asking you for the first time. This is one challenge for the caregiver and life enrichment. To somehow have **PATIENCE** and **REFRESH** yourself to answer their questions each time as if it is the first time they have asked it. Not to get exasperated, fed up or annoyed, but to cheerfully and matter of factly answer each time because this is the person trying to reach out and connect with you.

Humor

Humor is one of the keys to positive interaction for people with Alzheimer's. The ability to laugh and smile continues beyond the bounds of memory. Really, who doesn't like to laugh? Be curious about what strikes residents as funny and make a point to find what it takes to make someone laugh. At Emerson House we do an activity called "fishing on the net" where we gather around the computer and look up things that our residents might find interesting. And one day we stumbled upon vaudeville comedian, Henry Youngman. So I read the residents some of his jokes. I went to the airport and told the agent; send one my bags to London, one to Miami and one to Tokyo.

The agent said "we can't do that." I said "Why not? You did it last week." Well, my hotel room was lovely. The room was so small, when I put the key in the lock, I broke the window. The room was so small, the mice in my room are hunch backed.

This is a good activity that gets people laughing and smiling. We usually do this activity in the morning because we hope to set the mood for the day and what a better way to start than with a few laughs. Laughter really is its own reward. And laughing is healthy for mind, body, and spirit.

Always be **ENTHUSIASTIC!!!** It's hard to grab someone's attention without having enthusiasm. If you're working with someone who has Alzheimer's you need that much enthusiasm and more. Inviting a resident to an activity, you should show through your energy how much you would like to do this activity yourself.

At Emerson House, I like to describe activity like a soap bubble; very beautiful when everything is going smoothly but easily broken when disrupted. Try to keep anything that may break the "bubble" or focus of the group to a minimum. Be sure that caregivers and staff are aware and respect the activity going on and if they can, invite caregivers to join. Also, be aware of agitated resident. Gently remove him or her from the activity to a place that's lower in stimulation where they can become calm. Do anything you can to avoid bubble breakage.

Remember too, that sometimes not everything will make sense to us, when talking to someone who has Alzheimer's. And that's OK, validate it! Instead of trying to correct it, embrace the "not making sense". One way to do this is to write down some of the resident quotes that you may hear throughout the day that you find humorous or thought provoking.

Another form of validation that we use at Emerson House is "Grab Bag Poetry". Grab bag poetry is much like the word game mad libs, where we would write a poem based off of random Nouns, Verbs, Adverbs, and Adjectives drawn from the Grab Bag. We will also take songs and well know phrases and quotes and strip all the Nouns, Verbs, Adverbs, and Adjectives and replace them with words we draw. This gives expectation that it's ok, that not everything will always line up or make sense.

The term that we like to use at Emerson House is '**STOP MAKING SENSE.**' You may not know what the resident maybe talking about, but, **VALIDATE IT!** It is reality vs. validation. May not be real, may not be true, may not make sense, but that's ok.

Many times I'll come in to work, plan a whole activity, my residents will come into the activity room, I'll start the activity and by the time the activity comes to an end, the group is working or talking about something different than I planned. That's ok, go with it! Activities aren't always going to turn out how you planned. The point is to keep people engaged and stimulated, while at the same time feeling relaxed.

I was once told to think of a resident's day like the story of Rumpelstiltskin in a way. Except for the dungeon, the taking of the first born, etc. But somehow straw was spun into gold. This is what we need to try to do with our residents' thoughts and worries. Their concerns are the straw and our interaction and attitude will hopefully turn those worries in to gold.

Having a positive outlook, a sense of humor, and an approachable demeanor as we listen to the resident, can hopefully spin something that is confusing into something that will bring them ease. Because our residents often are confused, we need to try our hardest to have the right attitude to bring them comfort.

As we come in to our communities, our resident's homes, we need to remember that it is not our reality while we are spending time with them. We need to take a step back and truly listen to our residents and their reality. Also we need to try to spread this frame of thinking to our family members. If our resident's families can somehow find a solace in some of the nonsensical, or just the positivity and love of our communities, the process for them will be slightly easier. We find that when families have fully embraced the "stop making sense" mentality, and then their loved one passes and that chapter has closed, these family members have an easier time coping with the loss because they found some humor and optimism out of a disease that can be heartbreakingly bad.

