



## 40-Hour Basic Course For Activity Directors

# Alzheimer's and Dementia Activity Programs

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Home Instead Senior Care



# An Alzheimer's Disease Bill of Rights

Every PERSON diagnosed with Alzheimer's Disease or a related disorder deserves the following rights:

To be informed of one's diagnosis

To have appropriate, ongoing medical care

To be productive in work and play for as long as possible

To be treated like an adult, not a child

To have expressed feelings taken seriously

To be free from psychotropic medications, if possible

To live in a safe, structured and predictable environment

To enjoy meaningful activities that fill each day

To be outdoors on a regular basis

To have physical contact, including hugging, caressing and handholding

To be with individuals who know one's life story, including cultural and religious traditions

To be cared for by individuals who are well-trained in dementia care

The Best Friends Approach to Alzheimer's Care, by Virginia Bell and David Troxel.

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## Facilitating Effective Communication with Individuals with Dementia

As communication skills change with the progression of dementia, loosely identifying the level of cognitive functioning can be very helpful in choosing communication techniques to facilitate the best quality communication.

**Dignity and familiarity:** cornerstones of quality communication with every individual in any stage of dementia, “speak their language” choose words carefully (“Have you eaten yet?” vs. “Do you want a sandwich?”)

**Introduce yourself:** address the client directly, regardless of cognitive status, tell the client who you are and the role you play in the circumstances of the moment

**Sensory impairment:** can the client see and hear you as well as possible? Sit in front of client, at their level; maintain eye contact if possible

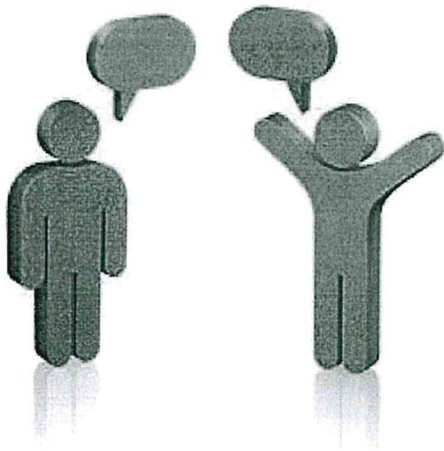
**Minimize distractions:** help the client stay on task, refocus as necessary, and avoid superfluous comments and questions

**Carefully consider the “truth”:** try to determine how much and on what level the client can manage the truth of a situation, be as honest as possible within the confines of their ability

**Concrete language/cues:** consider yes/no questions if you are fact finding, speak in the simplest, clearest terms possible (“how is your hip doing” vs. “does your hip hurt” while gently touching the hip)

**Timing is everything:** allow plenty of time for processing and responding – “silence is golden”

**Keep it conversational:** never “quiz” or say “do you remember?” or tell them that you have already given them information (“like I said . . .”)



**Read between the lines:** pay close attention to responses that may not appear “correct”, clues may be present

**Never talk about the client in front of them:** solicit additional or corroborating information from caregivers separately, try not to correct/reorient the client unless they ask for clarification

**Consider your facial expressions and body language:** you may send a message to the client that you do not intend; often clients are more attuned to non-verbal communication than verbal

**Less is often more:** stay within the client’s attention span, they may only be able to focus for one or two questions

**Actions speak louder than words:** consider that behaviors may say more than verbal responses they may be able to give

# Basics of Communicating with Demented Persons

The most basic rule of communicating with someone with dementia:

## KEEP IT SIMPLE!

Please DO!	Please DON'T!
<p><b>Pay attention to non-verbal communication!</b> Pay attention to body language, gestures of hands and arms, facial expressions and eye contact. Non-verbal communication can help you determine what a demented person needs or give you clues about their mood.</p>	<p><b>Don't "quiz" or ask questions that require them to remember!</b> "What time does your daughter come" or "don't you remember where you left your purse" or "you remember me don't you" will only embarrass or anger a demented person. Don't point out their mistakes or weaknesses!</p>
<p><b>Use simple words they understand.</b> Not "do you have to urinate?" but may understand "do you need to pee?"</p>	<p><b>Don't startle or surprise a demented person!</b></p>
<p><b>Give the demented person time to process what you have told them and respond to you. <i>DO NOT RUSH!</i></b> They will feel your impatience, and have a much harder time processing what you told them and responding to you. Rushing a demented person physically or cognitively will only make everything SLOWER!</p>	<p><b>Don't argue.</b> You will NEVER win an argument with a demented person! They do not have the ability to realize they might be wrong or have made a mistake! (Can anyone convince you that the sky is green and the grass is purple?) Arguing with a demented person will only agitate you and them!</p>
<p><b>Watch your tone of voice!</b> Speak kindly and respectfully. Using a demanding or demeaning tone of voice with a demented person will only bring on agitation and may provoke a catastrophic reaction!</p>	<p><b>Don't ignore repeated questions!</b> Ignoring an adult will only make them agitated! Often a repeated question is not only memory loss, a need for reassurance and comfort. A demented person may have lost their understanding of time don't remember they have asked the question a few minutes before.</p>
<p><b>Address the person by name and make eye contact with them!</b></p>	<p><b>Don't deliver bad news over and over!</b> Often when a demented person is talking about people in their past (parents, children, siblings, etc) it's because they are missing the comfort, reassurance and familiarity of those people. Each time you tell a demented person someone they love has died, it is often like they are hearing it for the first time! Instead of reorienting or correcting the person, speak to the emotion they are exhibiting "I can see that you really love your mom".</p>

<p><b>Use simple, short phrases!</b> Say exactly what you mean! Not “please sit down in that chair next to the table” but “please sit here”. Not “clean your plate” but “eat your peas”. Not “let’s get moving” but “come with me”.</p>	<p><b>Don’t talk about a demented person in front of them, regardless of how impaired they are.</b> You NEVER know what may be understood or how they may interpret what they hear!</p>
<p><b>Provide visual/physical cues.</b> Take the hand of a demented person and lead them to the toilet as you say, “Please sit down”. Show the person what you want them to do.</p>	<p><b>Too much is too much!</b> Monitor for distracting noises or activity. Is the TV on too loud, or is it distracting the demented person? Are the voices coming from the next room making it hard for the person to hear you?</p>
<p><b>Break complex tasks into simple, single steps.</b> Say “unbutton your shirt”, then “take your shirt off”, then “unbutton your pants”, and then “take off your pants”. Allow time between instructions for them to understand and respond to you.</p>	<p><b><u>Don’t ever give up!</u></b></p>
<p><b>Give simple choices!</b> Not “what do you want for dinner” but “do you want ham or chicken”! When possible, show them the two choices (hold up two sweaters and ask “do you want the red or blue one?”)</p>	
<p><b>Speak to them at their eye level.</b> If they are in a chair or wheelchair, bend or sit down! Standing over a person can be seen as threatening or as though you are treating them like a child.</p>	

**COMMUNICATION PROBLEM:  
I KNOW YOU BELIEVE YOU UNDERSTAND WHAT YOU  
THINK I SAID, BUT I AM NOT SURE YOU REALIZE  
WHAT YOU HEARD IS NOT WHAT I MEANT!**

## Behaviors and Dementia

**Keep in mind that ALL behaviors have a cause!** Look for the hidden meaning behind the behaviors! When you are working with any person who can not tell you how they are feeling or what their needs are, check the “basic needs”: **Hungry? Thirsty? Need the bathroom? Pain? Hot? Cold? Frightened?** Pain is the cause of many chronic behaviors that appear to have no other cause. Often people with dementia can't tell caregivers that they are sore or have chronic pain and so they become anxious or agitated. It is probably safe to assume that a senior with dementia is going to have some aches and pains that may be making them uncomfortable. It is always worthwhile to talk to the doctor about pain control.

**“The 5 W’s”** Become a detective and look for patterns or triggers. Try to determine if a behavior regularly occurs at the same time of day. (Maybe this is the time of day to routinely offer a snack, a walk, a nap or a favorite activity.) Does this behavior happen only in one place (the car, the bathroom)? Are there any “warning signs” (some demented persons will tell you “I am getting mad” or “I am tired of being here” or even “I am going to hit you!”)? Does she only get angry when she has to go to the bathroom or when it is time for a bath? Does she usually get combative when you try to cut her toe nails? Does he threaten you when you try to give his pills? Does he get aggressive before meals (hunger/thirst is a very common trigger of many behaviors)? MANY times, it is not possible to identify patterns or triggers of behaviors but it is always worth the time and effort to try!



**“The 5 W’s”**  
**What was the behavior?**  
**When did it happen?**  
**Where did it happen?**  
**What happened right before the behavior started?**  
**Who was present?**

**Not all behaviors are “problem behaviors”!** If no one is in danger, being hurt, threatened or disturbed, why attempt to stop the behavior?! Needless to say, if you have a person who sits and screams for long periods of time in a group setting; the behavior must be addressed in order to avoid the agitation and aggravation of others! When you are caring for demented persons, “pick your battles”! When so many tasks and care needs must be completed, your energy and time is very precious, choose the tasks that absolutely must be completed for safety, comfort and dignity (no one ever died from sleeping in their clothes or not getting a bath).

**Keep in mind . . .** frequently those people with dementia are more sensitive to our emotions than we may realize. If we are stressed, angry, and impatient, in a hurry or frightened, many times the demented person senses that things “aren’t okay” and can’t reason out why the caregiver is upset. Think about how a baby might “mirror” the emotions of the mother – often a baby begins to cry when the mother is upset because the baby understands is something isn’t “right”. If you are angry, you may get anger in return from your person with dementia!

**When in doubt – walk out!** When a person with dementia is upset it is usually almost impossible to proceed with much of anything! Ensure everyone is safe then back off! Giving both of you time to calm down and let the moment pass helps you refocus and decide what step to take next. This “breather” may also serve to shorten the behavior and make moving on occur much faster.





# THE GLOBAL DETERIORATION SCALE (GDS)

CLINICAL CHARACTERISTICS	
LEVEL	
1 No cognitive decline	No subjective complaints of memory deficit. No memory deficit evident on clinical interview.
2 Very mild cognitive decline (Forgetfulness)	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment of social situations. Appropriate concern with respect to symptomatology.
3 Mild cognitive decline (Late Confusional)	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
4 Moderate cognitive decline (Late Confusional)	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations occur.
5 Moderately severe cognitive decline (Early Dementia)	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.
6 Severe cognitive decline (Middle Dementia)	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e. loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.
7 Very severe cognitive decline (Late Dementia)	All verbal abilities are lost. Frequently there is no speech at all - only grunting. Incontinence of urine requires assistance toileting and feeding. Lose basic psychomotor skills, e.g., ability to walk. The brain appears to no longer be able to tell the body what to do. Generalized and cortical neurologic signs and symptoms are frequently present.

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## Resources, Bibliography & Suggested Reading

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Alzheimer's Association – National  
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[www.alz.org](http://www.alz.org)  
[info@alz.org](mailto:info@alz.org)

John Douglas French Alzheimer's Foundation  
11620 Wilshire Blvd. Suite 270  
Los Angeles, CA 90025  
1-800-477-2243  
[www.jdaf.org](http://www.jdaf.org)

**Alzheimer's Association – New Mexico Chapter**

9500 Montgomery NE Suite 209  
Albuquerque, NM 87111  
505-266-4473  
505-266-2195 - Helpline  
[www.nm-alzheimers.org](http://www.nm-alzheimers.org)

**Alzheimer's Disease Education and Referral**

(ADEAR) Center  
PO Box 8250  
Silver Spring, MD 20907-8250  
1-800-438-4380  
[www.alzheimers.org](http://www.alzheimers.org)  
[adear@alzheimers.org](mailto:adear@alzheimers.org)

**Children of Aging Parents**

1609 Woodbourne Rd. Suite 302A  
Levittown, PA 19057  
1-800-227-7294  
[www.caps4caregivers.org](http://www.caps4caregivers.org)

**Alzheimer's Foundation of America**

322 Eighth Avenue  
6<sup>th</sup> Floor  
New York, NY 10001  
1-866-232-8484  
[www.alzfdn.org](http://www.alzfdn.org)

**Family Caregiver Alliance**

690 Market Street, Suite 600  
San Francisco, CA 91104  
1/800-445-8106  
[www.caregiver.org](http://www.caregiver.org)

**National Institute of Mental Health (NIMH)**

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