

Tips and Techniques for Supporting Residents with Alzheimer's Disease Using the Habilitation Model: A Guide for Staff in Independent Senior Housing



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About the Alzheimer's Association of Massachusetts and New Hampshire

The Alzheimer's Association opened its doors in 1980 as one of the founding Chapters of the national association. In 2007, the Chapter expanded its responsibility to the inclusion of providing services to families and professionals living and working in New Hampshire. The Association is proud to be a strong statewide affiliate of the national Alzheimer's Association, the largest non-profit organization dedicated to supporting families and professionals and working to find effective treatments and a cure for Alzheimer's. As of the publication of this guide, there are more than 80 chapters of the Alzheimer's Association throughout the nation, assisting families, wherever they live. Visit us online at www.alz.org.

About JCHE

JCHE is proud to be Greater Boston's largest provider of Jewish-sponsored, non-sectarian housing for low-income elders, with 1200 apartments and 1500 residents in six JCHE buildings (three on one campus in Brighton). JCHE is internationally recognized for quality programs and services that enable the majority of the residents to live out their lives in their own JCHE home even as they face the challenges of increased frailty and the need for additional support services. JCHE provides exceptional affordable, supportive independent housing at our four sites in Brighton, Newton, and Framingham. Our residents have an average annual income of approximately \$14,000, with more than 93% falling into HUD's "low", "very low, or "extremely low-income" categories. The residents come from 23 countries and speak 20 languages. What makes JCHE special is its focus on providing opportunities for the residents to engage in physical, intellectual and social activities, programs and services.

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Medicare's "Habilitative/Habilitation Services"

This guide describes Habilitation Therapy as a model for working with people with cognitive impairment as developed by the Alzheimer's Association of Massachusetts and New Hampshire. **It is not related in any way to Medicare's Habilitative/Habilitation Services**, and is not reimbursed by any health insurance provider.

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Introduction

JCHE was awarded one of four inaugural Innovation Award grants from LeadingAge. The project was to learn about the Habilitation Therapy model taught by the Alzheimer's Association of Massachusetts and New Hampshire, used primarily to train aides and others in nursing homes, and adapt the model to be more appropriate and accessible to staff in independent senior housing.

This guide includes information about Alzheimer's disease, suggested methods and language for interacting with people with dementia based on the Alzheimer's Association of MA and NH **Habilitation Therapy** model. Not every method suggested in this guide will work with/for every person with dementia or every staff person. There will be successes and failures.

All of that having been acknowledged, people with Alzheimer's disease and other dementias already live in the buildings in which we work, they will continue to age with us in community, and their dementia will continue to progress.

We believe that the phrase “the whole is greater than the sum of its parts” applies to working with residents with dementia. Working as a team, including all staff that interacts regularly with the residents (resident service coordinators, maintenance, administrative staff...), and continually trying to find what works for each resident has proven to be a successful approach. The following five aspects and practices, which are reviewed in depth in this guide, will provide a common language and a way of addressing residents' needs for use with housing staff and families.

1. The Physical Environment
2. Knowing and Understanding the Individual
3. Our Communication with the Resident
4. The Resident's Communication with Us
5. Purposeful Engagement

Independent Housing

- Independent housing for older adults was and is not physically designed to support a population of residents with moderate to advanced dementia;

- Senior housing, especially federally, locally or municipally funded, does not have the additional funds to support the level of staffing required to properly care for a population of significantly impaired residents;
- Staff usually does not have the education or experience to support this group of residents; and
- The communities do not have the level of program activity that people with dementia need.

Today, there are woefully few slots in assisted living communities set aside for low income, cognitively impaired people, leaving nursing homes as the primary option. Often the need is for 24 hour **supervision**, rather than the need for 24 hour **skilled nursing care**. Sometimes, a resident's quality of life, as well as that of the person's family improves when that person enters a nursing home;

however, the majority of low-income, cognitively impaired people move to nursing homes because of the lack of other affordable options.

All of that having been acknowledged, people with Alzheimer's disease and other dementias already live in the buildings in which we work, they will continue to age with us in community,

and their dementia will continue to progress. This fact leaves an array of challenging behaviors for staff and other residents, which may create a disruption to the “peaceful enjoyment” of other residents. If the behavior is too troubling, the resident's tenancy may even be in jeopardy. Most important is to remember that the residents with dementia did not ask for the diseases that cause their dementia, and we, as housing providers, need to keep in mind how difficult memory loss is for the person who has it. At the beginning of the disease process, the person generally knows something is wrong. It is a depressing, frustrating and scary time. People often withdraw from friends, neighbors and favorite activities, spend a great deal of time alone, and hasten the worsening of disease symptoms.

Frequently the behavior of the resident(s) with dementia is troubling and bothersome to the staff and other residents, and often people do not know how to respond or help. And while adult day health and state-funded home care services fulfill a critical need for some, there are never enough low or no cost

options to keep someone with dementia engaged for all of their awake hours. But you probably already know that! The real question is: what can be done? The answer here, while not exhaustive, is multi-fold:

- educate staff in independent senior housing and others about working with/supporting people (particularly low-income people) with dementia;
- educate residents, families, and care providers;
- advocate for increased government funding for programs that delay/avoid nursing home placement such as 24 hour availability of adult day health;
- develop specialized, secured floors/wings within subsidized housing with the appropriate level of funding, staffing and activity

Most staff members make a distinction between themselves and the residents who live in the housing in which they work. While this distinction serves a purpose in terms of professionalism, it is important to understand that none of us is exempt from the things that happen to people, such as Alzheimer's. As you read through this guide, it is helpful to put yourself in the shoes of the resident with dementia.

Theoretical Framework: Habilitation Therapy Approach

Because most of the residents in your buildings are elders who come from a variety of educational, economic, cultural and linguistic backgrounds, it may be difficult to tell if changes in behavior and functional independence are caused by normal aging or some form of dementing illness. There are many reasons why someone's, particularly an elderly person's, behavior can change and we shouldn't automatically assume it is Alzheimer's disease. The role of housing staff may be to suggest a medical evaluation when changes in a resident's behavior are observed that seems uncharacteristic for that person.

It may be helpful to clarify some skills and terms that will give a frame of reference for evaluating what are normal changes and what may be more indicative of a neurologic disorder or other problem. Housing staff are not medical experts and should not make a practice of diagnosing residents; however, there are

basic assessment skills that are useful to determine if there is a change in a resident's behavior.

Basic Assessment Skills

Basic assessment skills are critically important when interacting with residents on an ongoing basis. Making these kinds of assessments takes practice, especially if you only see residents occasionally. Do you observe any significant changes? If so, it may be time to take action. Ask yourself the following questions.

A. Appearance

- Is the resident dressed appropriately for the weather? (e.g. wearing a parka when it is 90°)
- Are his/her clothes stained or dirty?
- Does s/he have an odor (e.g. cigarettes or alcohol; body odor; urine; excessive perfume)?

Most staff members make a distinction between themselves and the residents who live in the housing in which they work. While this distinction serves a purpose in terms of professionalism, it is important to understand that none of us is exempt from the things that happen to people, such as Alzheimer's. As you read through this guide, it is helpful to put yourself in the shoes of the resident with dementia.

- Has s/he been wearing the same outfit for several days in a row?
- Is the man unshaven or does he have an untrimmed beard (that is a change from his usual appearance)?
- Is the woman wearing unusually excessive make-up?
- Has s/he forgotten her/his cane, walker or other assistive device?

B. Speech

- Is what is being said logical?
- Is it fast-paced, agitated or hesitant with long pauses?
- Is it too loud or too soft?
- Does s/he stay on topic or keep changing topics?
- Does s/he speak clearly or mumble?
- Does s/he have difficulty answering questions?

- Is s/he using inappropriate language (e.g. swearing more than usual)?

C. Physical

- Is s/he pacing, fidgety, or agitated?
- Is s/he wringing her/his hands with anxiety?
- Does her/his face lack expressiveness?
- Does s/he smile or laugh while saying something very sad or worrisome?
- Does s/he stand too close to you?

D. Eye Contact

- Does s/he make normal eye contact by looking up or down at you or others as appropriate?
- Is s/he staring at you so you feel uncomfortable?
- Is s/he only looking straight ahead instead of in all directions?

E. Mood

- Does s/he appear sad/depressed or anxious?
- Is s/he crying uncontrollably?
- Is s/he unusually angry, hostile, or fearful?
- Does s/he report being upset, worried, fearful?

F. Cognition

- Is s/he oriented to date, time, and location?
- How is her/his short and long-term memory during normal conversation?
- Does s/he repeat her/himself frequently?
- Does her/his judgment seem intact (e.g. going outside without a coat in a snowstorm)?
- Does s/he express paranoid ideas (e.g. someone is out to get her/him)?
- Does s/he report seeing things or people that you can not see?
- Is s/he missing deadlines for rent checks or paying the wrong amount?

If you note changes or have concerns in any of the above areas, the first step is to make a determination if the resident is at risk to her/himself or others. If that is the case, follow the steps listed in the section below on “When is it time...”. If not, make a reminder to yourself to:

- Check in on the person in a few days
- Ask other staff members if they have any concerns about the resident
- Consider presenting the situation at a “Residents at Risk” meeting (see Resident at Risk section)
- If you are still concerned the next time you see the

resident:

- Encourage the resident to see a physician
- Set up a meeting with the resident, who may be accompanied by a family member, service provider, or friend, to express your concern. If the resident does not agree to meet, ask her/him to permit you to contact a family member or service provider
- Bring the concern about this resident to a “Residents at Risk” meeting.

If you or other staff feels that the resident’s behavior has changed, ask yourself the following to help you decide when it is time to intervene.

The role of housing staff may be to suggest a medical evaluation when changes in a resident’s behavior are observed that seems uncharacteristic for that person.

When is it Time

When is it time for housing staff to intervene? Look for these behaviors:

- Repeating questions or stories
- Inability to keep track of everyday tasks
- Wandering (indoors or outdoors)
- Withdrawal from activities
- Obvious visual changes – the resident is looking straight ahead instead of in all directions
- Making paranoid or delusional comments
- Making comments that lead you to believe the resident is hallucinating
- Any behavior that affects staff or other residents’ right to the peaceful enjoyment of their homes like repeated knocking on other residents’ doors during the night
- Repeated calls to staff and/or emergency personnel (i.e. police, fire, ambulance)
- Decrease in personal hygiene (e.g. strong body odor, signs of incontinence)

When is it time to involve others (family, medical professionals, protective services...)?

- If a resident acknowledges being increasingly forgetful, depressed, or in psychological distress, with her/his permission, contact family (if there is any) to refer her/him to a medical professional for a full medical workup and neuropsychological assessment and treatment if indicated.
- If you have concerns about the resident’s ability

	Normal age- related memory changes	Depression	Alzheimer’s disease
Memory	Forgets parts of an experience	Has impaired concentration and worries about memory	Forgets whole experiences and can’t remember short-term information (e.g. what s/he had for breakfast)
Memory and Mood	Forgetting may be frustrating, but the person often remembers later and usually does not have a “layer” of other emotion.	If memory is impaired, her/his mood is depressed. And, depression as a primary diagnosis can affect memory	Rarely remembers later. When memory gets worse the person may become irritable and/or exhibit a flat affect
Orientation	Oriented to time, place and person	Usually oriented to time, place	Not oriented, confused Gradually unable to follow written or spoken directions
Language	Able to use notes and able to follow written or spoken directions	Speaks, writes and uses language appropriately and able to follow written or spoken directions	Gradually unable to use notes. Has difficulty naming objects and can not use them properly (e.g. s/he says “Hand me that thing. You hand her/him a toothbrush and s/he uses it to brush her/his hair)
Self-care	Able to care for self	Is usually able (depending on physical ability)	Gradually unable to care for self
Decision Making	Is able to make decisions	May have difficulty, but is able	Able in the very beginning, not as able with progression, then unable
Awareness	Is aware	Is aware	Aware in the very beginning, not as aware with progression, then unaware

to care for herself/himself safely, encourage the resident to agree to let you speak to a family member or the her/his care provider (primary care physician).

- If the resident refuses to allow you to contact anyone and you feel s/he might be at risk, contact your state’s or local area’s protective service unit.
- If the resident is in a mental health crisis, making suicidal or homicidal statements, physically assaultive, acutely delusional, or unresponsive, contact your local mental health emergency system or the police (911) immediately.

There are many diseases, like Alzheimer’s disease that can cause the condition of dementia. **Dementia** can be thought of like the term “blindness”. Blindness is a condition that is caused by a number of different diseases, cataracts, glaucoma, and diabetic retinopathy and so on. Dementia is a condition that

can be caused by a number of diseases... some of which may be treatable medical conditions and others may be neurological brain diseases where there is no cure, like Alzheimer’s disease. Alzheimer’s disease is the most common cause of dementia, accounting for 60%-70% of the cases. Technically speaking, Alzheimer’s disease is a progressive neurological disorder that damages vital areas of the brain and results in the person’s death.

There are a number of related, but very different, neurological diseases that may look like Alzheimer’s disease at first, but as these diseases unfold, they have a different array of symptoms and present the housing staff and fellow residents with different issues and concerns (See Appendix for “When it’s Not Alzheimer’s). It is important that you encourage the person who is experiencing cognitive difficulties and/or their legally responsible others to seek

medical attention to look at the underlying cause for a change in the person's behavior, memory or everyday functioning. However, it may be difficult for senior housing staff to know the difference between normal age-related changes in thinking and behaving and what changes might be caused by a disease like Alzheimer's.

Is it Normal Age-related Changes, Depression, or Dementia?

Several of the symptoms of depression, dementia and normal age-related changes are related to changes in the way we think or understand information. Knowing whether the main problem is normal age-related changes, depression, or dementia is often difficult. When people are diagnosed with early stage dementia, they generally know that they are losing their memories. This loss is devastating and can lead to depression. Major depression can include symptoms that imitate dementia, and many symptoms of dementia overlap with those of mental illness.

Typical Warning Signs of Alzheimer's Disease:

- Changes in memory
- Changes in visual memory and visual tracking across the visual field
- Changes in orientation to time, (day, season, year) place (getting lost) and later, person (relationship to others)
- Changes in language, word-finding, slower speech, trouble paying attention to language
- Changes in the ability to carry out everyday tasks, like cooking or bill paying
- Changes in mood and personality
- Changes in judgment and reasoning, awareness or insight
- Changes in behavior that may be atypical of the person in the past
- Emotions are harder to control
- Withdrawal, depression
- Delusion, hallucination, or paranoia

Examples:

Normal Age-related Changes

Mrs. Celia Lombardi is a 79 year-old widow who lives alone in senior housing. While talking with friends recently, she told them of her trip to Italy two years ago. She remembered many of the family she visited. She met her cousin's baby granddaughter while on the trip. As hard as she tried, she could not remember the baby's name. Later she remembered the baby's name—Josephina! Mrs. Lombardi sometimes forgets the names of people she just met, but she will

recognize them if she sees them. The names often come back to her later. She still cooks and pays her bills. She writes notes and keeps a calendar to track appointments and errands. It takes her a little longer to learn new things than when she was younger.

Dementia

Mrs. Louisa Tancredi is a 79 year-old widow who lives alone in an apartment. She is an excellent cook and housekeeper and is always particular about her appearance. She has had a loving and easy relationship with her daughter, Elizabeth. When Elizabeth arrives for a visit from California, she is surprised that her mother has forgotten she was coming. They had talked on the phone about the visit a number of times in the past couple of weeks. Elizabeth also notices that her mother is not taking good care of herself. Her hair is greasy and her clothes are dirty. The refrigerator is filled with spoiled food. There are piles of bags and newspapers everywhere. Elizabeth asks her mother what is wrong. Mrs. Tancredi becomes angry and says to Elizabeth, "Why don't you mind your own damn business."

Unlike Mrs. Lombardi, Mrs. Tancredi is experiencing more than normal age-related memory loss.

- She is forgetting more than just parts of experiences
- She needs more than just notes and reminders to keep to her schedule
- She is experiencing changes in her normal behavior as evidenced in her housekeeping and personal hygiene habits
- She is experiencing changes in her mood and is disinhibited

Your ultimate goal is to determine if the person who is experiencing changes in thinking and behavior can continue to be maintained in your building longer (even if there is an impact on the other residents) by providing the resident with additional coordination of support services and specific staff training on dementia care and behavioral management techniques. The needs of the resident whose behavior has changed can be quite varied. These needs will depend on the individual's personal history and coping style, the stage of their dementia, and, in many ways, the type of dementing disease with which the person is dealing.

Overview of Alzheimer's Disease

- The baby boomers, those born between 1946 and 1964, are now coming to the age where they are at an increased risk for the disease.
 - Age, itself, is a significant risk factor for the disease. It is estimated that one in nine (11%) over age 65, and about one third (32%) of those 85 and older have the disease.
- As of 2014, there are more than five million Americans with Alzheimer's disease and this number is expected to double, if not triple, over the next twenty years.
 - A number of social and demographic elements are coming together to cause "The Alzheimer's Perfect Storm."
- The "Alzheimer's Perfect Storm" also reflects an improving awareness within the medical community to screen for Alzheimer's disease regularly.
 - There are now a number of "bio-markers" or indicators, that when taken together can lead to a more accurate diagnosis of Alzheimer's disease. While still in limited use, in the coming years physicians will use these tests more regularly in making a diagnosis of Alzheimer's disease.
- Finally, the public is now more aware of Alzheimer's disease and the stigma associated with the disease is lessening - so more will seek a diagnostic evaluation.
 - Today only about 50% of the people who have Alzheimer's disease actually receive a diagnosis, and 50% of those who are diagnosed receive the diagnosis very late in the course of the disease, often in a nursing home.

So, by mid-century we will have between 10 and 15 million Americans who will be living with Alzheimer's disease.

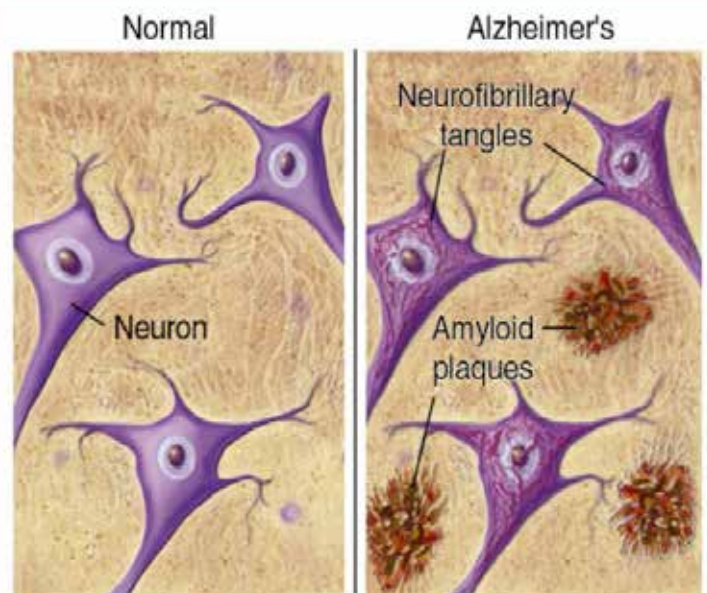
It is estimated that today there are 15 million family caregivers who contribute 17 million hours of unpaid care to their loved ones with Alzheimer's disease. The cost for Alzheimer's care provided by Medicare and Medicaid today is 1.8 billion dollars per year, and it is expected to be more than a trillion dollars per year as the numbers of those diagnosed increases. If the progression is as expected, the number of people who have Alzheimer's disease will double by 2034.

There are a number of identified factors that contribute to an individual's chances of being diagnosed with Alzheimer's disease.

- | | |
|--|---|
| • Age, the older you are the higher the risk | • Diabetes |
| • Family history and genetic risk factors | • Head Injury with or without concussion at any age |
| • Cardiovascular disease | • Depression/Anxiety Disorder/Chronic Stress |

What Happens in the Brain

Alzheimer's is a neurological disease that affects most of the brain. A protein called **beta amyloid** accumulates forming dark colored clumps, called **plaques**, outside of neurons, which are the cells in the brain that are most involved with thinking, sensing, perceiving, feeling, planning, language, movement, and many other essential life sustaining function. Plaques cause brain cells to die. At the same time, another protein, called **tau**, which make up the walls of the neuron erode and form what are called, **neurofibrillary tangles** which look like tangles of spaghetti under the microscope. This process of forming plaques and tangles, which is referred to as the neuropathology of Alzheimer's disease, starts many years before we see any outward symptoms of the disease. Some research suggests that the neuropathology of the disease begins 10 to 15



years prior to any noticeable changes in thinking and behavior.

By the time the person with Alzheimer's dies from the disease, a period that takes anywhere between 3 to 18 years, he or she will have lost 2/3 of their brain weight. The normal brain weighs 3 lbs. and a brain ravaged by Alzheimer's disease will weigh about 1 lb. at the time of death.

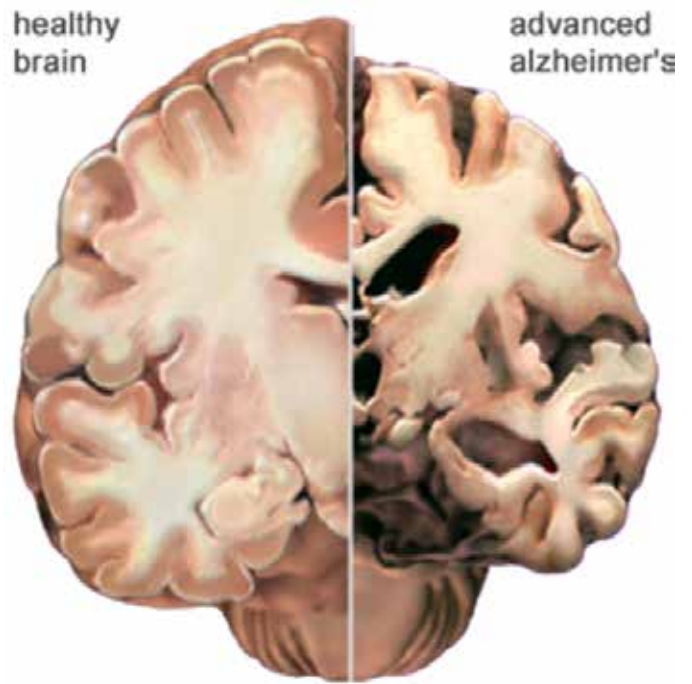
- The disease starts in the **Hippocampus**, the area of the brain just above the ears on both sides of the brain
- The hippocampus is responsible for processing new incoming information and putting that information that comes in through the senses in a form that the brain can use
- As the disease progresses the person becomes unable to remember any new information. The disease involves most of the brain over time.
- The hippocampus is particularly involved with memory, thinking, decision making and reasoning. In the early stages of the disease the hippocampus is not working reliably. The person cannot always process the new incoming information or experience, and hold them in memory.

For example, there are profound symptoms associated with vision. The person may lose depth perception, the perception of certain colors may be lost, so that by mid stages of the disease the person may be only able to see the bright primary colors, red, yellow, blue, and the other colors are seen as various shades of gray. By mid-stages of the disease, the person requires 100% more light to see at the acuity as the same aged person who does not have Alzheimer's disease.

The disease also affects the front part of the brain, called the Frontal Lobe, that area that deals with planning and carrying out multiple step tasks. This part of the brain controls our judgment, especially in social situations. So, some people with Alzheimer's disease might display socially inappropriate behavior, because of damage in the front part of the brain.

Experiencing paranoia (unrealistic fear), delusions (thinking something is true that is not true), hallucinations (seeing, hearing, smelling, feeling something that isn't real) can

occur when the front part of the brain is damaged. Most Alzheimer's patients will have significant difficulty with planning and carrying out tasks and at some point require assistance with their everyday



tasks of life, such as cooking, bill paying, dressing, shopping, bathing, finding one's way in the building and getting lost, toileting, decision making, social engagement, and so on.

Due to ongoing damage in the front part of the brain the person with Alzheimer's may lose insight into their situation, and not be able to recognize that they have a problem with memory and thinking. In other cases, the affected person withdraws from family, friends and limit social involvement because they are aware of their dementias and not want to embarrass themselves in front of those people.

The disease affects language, both the person's ability to understand language (a speed of brain processing problem) and producing language (a problem with expressing a thought, with forming the words and accessing the words you want to use). By end stages of the disease both expressive and receptive language will be mostly lost.

The hippocampus is particularly involved with memory, thinking, decision making and reasoning.

As the disease progresses, it compromises those areas of the brain that support how the body maintains itself. Because of what is happening in the brain,

The amygdala is involved with emotions: the ability to hold an emotion; the ability to perceive emotions in others; the ability to feel emotions and the need to evoke and receive emotions in others.

tasks like cooking and shopping, Paying bills may take longer to accomplish with more effort required. There are problems at this stage with the person's sense of time, time of day, day of the week, year, appointments, etc.

basic organ functions and reflexes like fighting infections, respiration, or swallowing may be lost in the later stages of the disease, causing death.

Given all this damage in the brain, there is one area, called the **Amygdala**, which remains pretty much intact long into the progression of the disease. The amygdala is involved with emotions: the ability to hold an emotion; the ability to perceive emotions in others; the ability to feel emotions and the need to evoke and receive emotions in others. It is through emotion that we can build connections with the person with Alzheimer's disease because that part of the brain is still functioning. Using reasoning or trying to teach the person what he or she should or should not do may not be the best approach, because these parts of the brain (the hippocampus and the frontal lobe) are impaired early and profoundly in the disease. It is by establishing an emotional connection with the person that we can make the most profound changes in order to keep the resident safe, more independent, and appropriate to remain in senior housing, even for a few months longer. It all has to do with what areas of the brain remain intact that we can use.

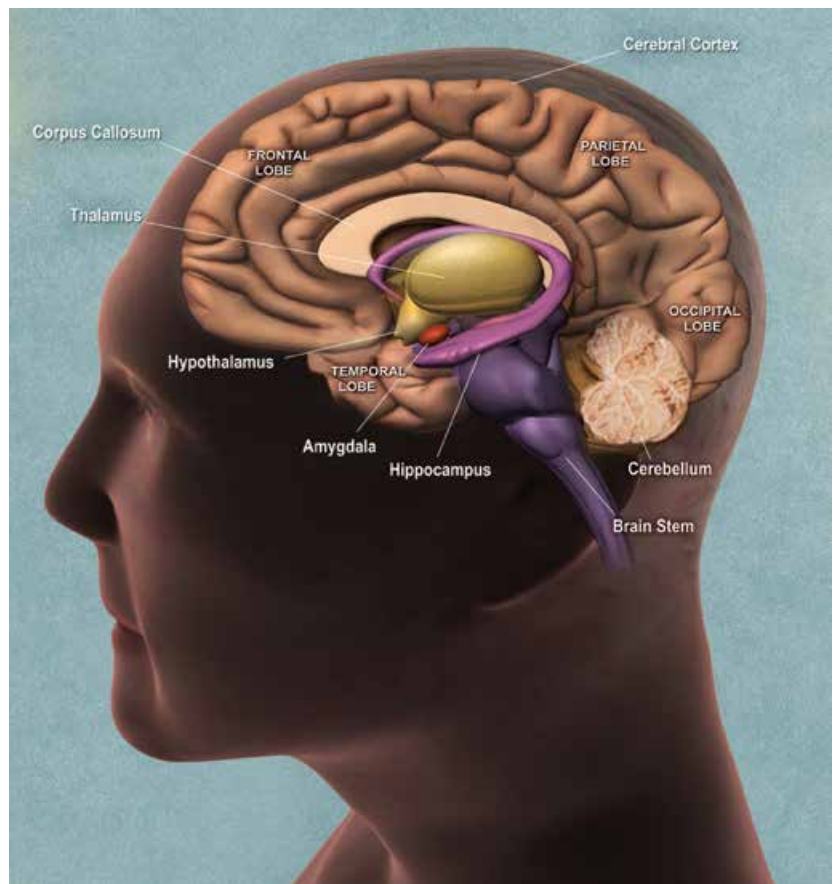
Stages of the Disease

There are several different ways of thinking about the stages of Alzheimer's disease, but for the purposes of this guide, it is perhaps most useful to discuss the progression of the disease in three phases: early, middle and late stages.

In the early stage of the disease the person most likely has problems with short term memory, finding the right word quickly, maintaining attention, learning new things as easily as before, remembering the names of new people, losing or misplacing things, a lowered threshold to frustration, symptoms of depression that might include withdrawal, altered sleep patterns, changes in appetite, and, everyday

In the early stages of the disease the resident may need assistance in one or more areas in order to remain in independent housing longer.

- Setting up and managing homemaker services
- Providing groceries that are simple to cook
- Reminding people about communal meals and social events
- Assisting with bill paying
- Setting up large calendars for scheduling events



and appointments in the apartment and labeling cabinets and drawers

- Setting up a medications dispenser
- Organizing a list of frequently called telephone numbers in large print by the phone
- De-cluttering the apartment if needed



The middle stage of the disease is characterized by significant problems with short term memory and the ability to learn new things. In this middle phase of the disease the person with Alzheimer’s disease will lose a significant amount of long term memories, such as milestone events in one’s life, the names of significant others, the history behind one’s personal relationships. Here is where we see increasing difficulty with the very basic everyday tasks of life, like dressing, bathing, toileting, walking, eating and personal care. By the end of this middle stage the person will require assistance with each of these activities of daily living. During this stage the person will experience increasing problems with “way finding” and will get lost easily. While the sense of time is impaired in the earlier stage, the senses of place, where the person lives and his or her history in that place diminishes or vanishes. Towards the end of middle stage disease, the sense of person is lost.

During middle stage disease **some** residents may be able to remain in your building if you can arrange for or tap into **some** of the services listed below that might enable them to remain in their apartments, and

out of a nursing facility longer: even if only for a few months.

- Assistance with preparing meals or getting to communal meals
- Turning off the stove
- Assistance with organizing their apartment and taking away clutter
- Making sure food in the apartment is not spoiled
- Seeing that sealed containers of water, fruit and non-perishable snacks are placed in plain view within the resident’s apartment for nourishment if a meal is missed
- Reminders of appointments and schedules
- Daily safety checks or telephone calls
- Assistance with grooming, bathing, dressing
- Homemaker services
- Medication reminders
- Visual images of the food choices in the dining room
- Training of the food services staff in dealing with residents with memory problems
- Transportation/Accompanying the person to medical appointments
- Assistance with shopping

- Assistance with bill paying
- Arranging for participation in a social day or adult day health program for something to do during the day
- Arranging the use of appropriate technology (wander bracelet)
- Registration in the Alzheimer's Association's Medic Alert/Safe Return Program

Check to see whether the local chapter of the Alzheimer's Association has a telephone check in service that might call the resident on a regular basis to see how s/he is doing. You may also check with the chapter to see if they could provide training for your cognitively intact residents about how to be a friendly neighbor for someone in the early stages of Alzheimer's disease. Having a trained, sensitive neighbor who checks in with the resident daily can help to keep an early stage resident more independent and less of a burden to other residents.

It is by establishing an emotional connection with the person that we can make the most profound changes in order to keep the resident safe, more independent, and appropriate to remain in senior housing, even for a few months longer.

The late stage is marked by significant problems with movement and an array of serious medical problems. The person in the third stage of the disease may only be appropriate to live in independent housing with 24-hour in-apartment care and/or hospice care. In most cases, the person in the late stages of Alzheimer's disease might be better served in a long term care facility.

How do you know when the resident may be unsuitable to remain in senior housing because of late stage Alzheimer's disease?

- When the resident experiences a number of falls caused by diminished visual, motor, judgment issues caused by the dementia

- When the resident is unable to feed him or herself, experiences significant weight loss, has problems with swallowing
- Is incontinent of bowel and bladder and resists assistance with personal care. If incontinence causes a health risk to others
- When the resident requires a lift to assist them in and out of bed or bed to chair
- When the resident experiences an ongoing fever of unknown origin
- When the resident requires round the clock nursing supervision
- When there are a number of emergency hospital visits over the course of a month or two
- When the resident's behavior impacts the quality of life of other residents after several interventions to address the behavior have been tried with little impact
- The resident could be made more comfortable in another setting
- The resident's medications can not be reliably administered and monitored in the housing setting
- The resident would be better served in a hospice or palliative care facility





Habilitation Therapy

Habilitation Therapy

Habilitation is not Re-habilitation which refers to restoring function; rather “habilitation” refers to maximizing the person’s capacity at any point in the course of their disease—to draw out all the person’s cognitive, social and coping skills throughout the course of Alzheimer’s disease, early, middle, yes, even in later stages of the disease. Because the part of the brain that deals with basic emotions, the amygdala, remains intact for most of the disease, the way to help the person with Alzheimer’s disease is to connect with them emotionally, not necessarily rationally. Therefore, the goal of Habilitation Therapy is to bring about a positive emotion in the person with dementia and avoid negative emotion that is often caused by our insistence on bringing the person back to our sense of reality or insisting that they change in ways that they cannot. Sounds simplistic, but it often takes some practice and patience to develop the skills within the Habilitation Therapeutic approach.

We’ve broken down Habilitation Therapy into a series of domains or aspects. A domain is simply an area in which you have an opportunity to bring about a positive emotion and avoid a negative emotion.

1. Knowing and Understanding the Individual
2. The Physical Environment
3. Our Communication with the Resident
4. Purposeful Engagement
5. The Resident’s Communication with Us

Because the part of the brain that deals with basic emotions, the amygdala, remains intact for most of the disease, the way to help the person with Alzheimer’s disease is to connect with them emotionally, not necessarily rationally.

1. Knowing and Understanding the Individual Personal Preferences

Knowing and understanding the person with dementia is extremely important. Think about yourself - if you were no longer able to ask for what you wanted or able to express yourself, wouldn’t you want someone close by who knows you and your preferences? While it may not be realistic for all housing staff to know and understand every resident,

there are opportunities for housing staff to use the Habilitation model to work with one another, care givers, family members and other residents to support the cognitively impaired resident.

There are so many personal preferences that we take for granted because we are able to communicate our wishes, or help ourselves. Just think about this one example – coffee.

Habilitation is not Re-habilitation.

How do you take your coffee?

- Do you make coffee at home; or do you prefer Starbucks, Dunkin’ Donuts, Honey Dew Donuts, White Hen Pantry or other?
- Do you drink regular or decaf? Does it depend on the time of day?
- Do you drink it black or with 1%, 2%, half and half, whole milk, cream?
- Do you add sweetener? If so, one sugar, two sugars, artificial sweetener, if so which one?

Even in this tiny example, there are so many possibilities and personal preferences! It is clear that personal preferences really matter! Yes, knowing the person with dementia may be difficult for a whole host of reasons such as having the person move into your community when s/he already has dementia and not having family or friends to ask about the person’s life before dementia. But there are strategies to get to know the person including talking with others, such as friends, family, staff, neighbors and looking around their apartments for clues about their interests and experiences. Gather as much information as possible when the resident moves in concerning the categories below. Again, think about yourself. What would you want people to know about you if you could not tell them? What makes you... YOU?

There has been a long-standing idea that independent senior housing, particularly government funded, could not ask residents about their lives, medical or otherwise. However, this thinking has changed over time, and now many housing management companies make it a common practice. The most important thing is that the resident gives permission

to management to collect this information. With the residents' authorization and release, we recommend using the questions below to "get to know" the resident. Use your judgment as to which questions you ask, who should be the asking, or which questions you think are not appropriate. Obviously, if the resident already suffers from dementia it may be impossible to obtain this information from her/him, so it is best to use other sources as well. See Appendix 5 for the form.

Basic information:

- What name do they like to be called?
- How old are they?

Family history

- Where did they grow up?
- Did/Do they have siblings?
- What was their number in the birth order?
- What size was their family of origin?
- Did they grow up with both parents and/or grandparent(s)?
- Were they close with their parents?
- What did their fathers and/or mothers do for work?
- Were their grandparents an active part of their lives?
- Are/Were they close to their relatives/cousins?
- Are/Were they married?
- How/Where did they meet their spouse?
- How long have they been or were they married?
- Were they married more than once?
- Do/Did they have children, grandchildren, great-grand children?
- Did they take family vacations?

Education, work and social history

- What was the highest level of education they achieved?
- Did they go to college or technical school, if so where?
- What did they do for work?
- When did they retire?
- What work did they enjoy (house work, yard work, handyman tasks, ceramics, painting...)?
- Did they receive any awards or special recognition of achievement?
- Did they belong to any clubs or organizations?
- Are they veterans, if so what was their service?
- What do they like to do in their free time?
- What activities do they find the most relaxing?
- Do/Did they have a group of friends that regularly did things together?

- Do they prefer to spend time with many people, few people, alone?
- Who are their friends?

Religious affiliations

- Did they practice a religion?
- Did they attend a house of worship?
- Do they enjoy religious music?
- Do they have a favorite hymn or song?

Think about yourself - if you were no longer able to ask for what you wanted or able to express yourself, wouldn't you want someone close by who knows you and your preferences?

Physical and cognitive abilities

- Are they able to walk, assisted or independently?
- Are they able to communicate their needs?
- Do they use any assistive devices?
- Can they read? If so, what do they like to read?
- If they can no longer read, would they still enjoy looking at a newspaper, magazine or book?
- Can they write?
- Do they have visual or hearing problems?
- On a scale of one to five, how is their short-term memory at move-in?
- Are they able to follow simple directions?
- Do they suffer from hallucinations, delusions or paranoia?

Personalities

- Were they typically outgoing or were they reserved?
- Did they like to be "in the spotlight"?
- What makes them laugh?
- Do they like to lead or follow?
- Do they get angry easily?
- What is their demeanor most of the time?

Observation/Assessment

Staff should share as much information with one another on an ongoing basis as possible concerning all of the information gathered about a resident. Play a game at staff meetings called "Do you know" about the residents' preferences and experiences. Observe the residents as often as possible to see if any changes are detected. Question if those changes are the progression of the disease, or another problem that needs to be addressed (e.g. pain, constipation, infection, ill-fitting dentures, too long toenails...).

Determine if a phone call to the family or physician is appropriate. With the resident's or family's permission, speak to others such as case managers or service providers to gather information. Share with other staff members if you believe a resident is "at risk" (See Appendix 4 for Resident at Risk description).

Prostheses, in general, help a person compensate for a loss or disability (e.g. dentures, canes, walkers,

Again, think about yourself. What would you want people to know about you if you could not tell them? What makes you... YOU?

2. The Physical Environment

Let's say you were late for a critically important professional presentation you were making in a building you had never visited before and the signage at the bottom of the page is what you came across when searching for the right room:

Would you stay calm? Would you get agitated? Would you seek out someone to ask? Would you show your frustration or anxiety? Imagine what it is like for someone with Alzheimer's disease - everyday things look confusing, and they may not have the ability to get clarification from someone.

A well-planned physical environment is one that compensates for what we know to be the sensory losses of people with Alzheimer's - seeing, hearing or understanding what is around them. With Habilitation, the physical environment is one of the important things we can change to help a person with dementia understand and feel positive feelings. Our efforts can make the person with dementia feel safe and secure, and feel a positive emotion.

prosthetic limbs, glasses, hearing aids, etc.). We know that people with dementia have a harder time figuring out how to manage because parts of their brains are not functioning. Remember the 1 lb. brain of someone at the end stage of Alzheimer's? Making significant changes to the physical space is not a reasonable expectation for independent senior housing communities, particularly subsidized, but we need to do as much as we can to compensate for these sensory losses.

Visual compensation includes:

- Having twice as much light as needed for normal older eyes
- Lighting that throws no shadows or glare
- Having color contrast between things (tables/plates/placemats, walls/floors/doors, walking paths, toilets...)
- Cues to help with way-finding, such as:
 - Having well-lit paths from bedroom to bathroom at night
 - Marking the apartment doorway with a different color paint or poster
 - Painting doors within the apartment and around



A well-planned physical environment is one that compensates for what we know to be the sensory losses of people with Alzheimer's - seeing, hearing or understanding what is around them.

- the building so they can find them
- Creating memory boxes outside the apartment door or other “reminder features”

Hearing compensation includes:

- Limiting noise (TV, radio, crowds, buzzers, alarms...)
- Having a quiet place to which residents can be pointed or escorted
- Limiting exposure of some residents with dementia to high-volume entertainment (drums, jazz, horns, opera...) or large gatherings of people as appropriate for those individuals

Physical Layout and Considerations

- Making clear paths, free of distractions (e.g. bed to bathroom, apartments to dining or community room...)
- Closing doors to rooms that are not needed or are unused (e.g. closets, 2nd bedroom, offices...)
- De-cluttering (i.e. helps with seeing, finding things more easily, and mobility)
- Limiting distractions (e.g. when in bathroom - too many bottles of soaps, lotions, and creams)
- Making what they need easier to find or use, giving a sense of independence
- Being mindful of light:
 - Light coming in through a window can blind the person or limit what the person can see
 - Glare on a highly shined floor may be perceived as water or ice and the person with Alzheimer's will try to step around it, but the reflected glare moves too, which could lead to a fall
- Patterns on flooring can also cause confusion and lead to falls. Plain carpeting or vinyl presents less of a problem for those with dementia.
- People with Alzheimer's disease lose depth perception; therefore, a dark area on the floor surrounded by a lighter colored area is often perceived as a hole or a pit. The resident may use her foot to test whether the dark area is a hole or a stair. This can sometimes

cause a fall.

- By mid stage Alzheimer's disease the person may lose the perception of most colors other than the bright primary colors like red, yellow and blue. Use these colors to make important features of the environment stand out.

A resident who had only been living at the community for a short time had dementia that was getting worse. Her family asked us if we could remind the resident to brush her teeth. As this is not a task that we would normally do, we let them know that one thing they could try would be to leave her toothbrush and toothpaste together on the vanity in the bathroom, perhaps in a brightly colored, sturdy plastic cup.

Case Example

The symptoms of a long-time resident with dementia were getting worse. When a maintenance man went in to the apartment to change the ventilation filter, he reported to the RSC that there was a urine odor in the apartment. A RSC visited the resident and brought the problem to the Memory Support Team who determined that during the night, the resident was either mistaking the closet for the bathroom, or the resident was incontinent, soiling his clothes or shoes, and then returning them to the closet. We opted to contact his family, based on his degree of dementia and our previous interaction with them. They understood that we wanted to partner with them to help their father remain a resident. Several things could be tried to provide cues and clues to this resident to make his way to the bathroom to urinate in the toilet:

Making significant changes to the physical space is not a reasonable expectation for independent senior housing communities, particularly subsidized, but we need to do as much as we can to compensate for these sensory losses.

- His homemaker could regularly launder his clothes (if there is family, this task could be shared)
- The closet door could remain closed (a closure or lock could be installed on the closet door)
- A night light could be left on in the bathroom to draw his attention to it
- The wall behind the toilet could be painted a bright color
- The white toilet seat could be replaced with a red one
- A sensor could be installed to turn a light on in the bathroom, which could be activated when he steps out of bed
- If the resident has an evening aide, the aide could remind and assist him to use the bathroom before s/he leaves for the night

3. Our Communication with the Resident

Before we begin the section on our communication with the resident, it is important to explain what happens to us when we witness an odd or disturbing behavior and do not understand what is going on. We expect people to behave in certain ways and in accordance with certain social and cultural norms. We also expect adults to be responsible for their actions. In fact, one meaning for the word “behavior” is to control one’s actions. When we observe behavior that is bizarre or doesn’t seem culturally appropriate, we are affected psychologically and physically. Our muscles tense, our body language changes, our eyes dilate, and chemicals in our brains and bodies signal the need for greater alertness to

possible danger. Our brains race as we try to resolve the state of psychological and physical alarm by attributing the most likely rational reason for the behavior that has been observed. When we do this, we often attribute the wrong cause to the behavior. We then communicate to the resident our emotional state, which may cause the resident to become upset. Instead, we must take a step back, and realize that the only way to change the resident’s behavior is to change what we do.

With dementia, not all behavior has a rational cause, or at least a cause that seems rational to us. We must be mindful of our reflexive reactions before addressing the behavior of someone with dementia.

Spend 5 to Save 20

We all have work that needs to be done - sometimes in our offices and sometimes in the residents’ apartments. Maintenance staff have preventative work to do such as changing filters, staff have to re-determine residents’ income each year, and staff occasionally need a signature for one thing or another. As we have been exploring, working with cognitively impaired residents has its challenges. Sometimes it is difficult to get a resident to focus on the task at hand, such as allowing staff access to the apartment. Spend 5 to Save 20 suggests that we take the time to establish rapport and connect with the resident on their level with conversation or any appropriate means (looking at a photo album, making comments about photos in the apartment...) using the techniques described in the communication section. The goal is

Asking Questions that Lead to Successful Communication

We strive to create opportunities for success with communication that is dependent on the person’s level of cognition and ability. We must keep the person’s remaining skills in mind to create the Habilitation goal of promoting positive emotion. If you know the person, you will know which type of question will give the best possibility of a good emotional experience, as well as limit the frustration, anxiety or other negative emotion. There are three types of questions to achieve this goal:

Open ended	Two choices	Yes/No
Where do you want to sit?	Do you want to sit by the window or by the kitchen?	Do you want to sit here?
What do you want for breakfast?	Do you want pancakes or waffles?	Do you want pancakes?
What sports do you like?	Do you like baseball or hockey better?	Do you like baseball?

Use the appropriate type of question to get the most out of the communication with the resident and set up the communication for a positive emotional response. Asking too difficult a question (open ended) for a person with very limited ability to respond appropriately sets the resident up for frustration and reinforcement of inability.

to put the resident at ease. Let them know that you know them and it is okay to do what you are asking of them. Ultimately, it will take a shorter time to get done what you need to by spending a bit of time with the resident up front.

how we feel, so all parts of our non-verbal and verbal communication have to match.

- Body language
- Eye contact
- Facial Expression
- Proximity to/Distance from the person

Be Mindful of Non-Verbal Communication
Our non-verbal communication can tell the resident

Connect, Refocus and Redirect

The way to connect with the person with dementia is through emotions by empathizing with the feeling s/ he is experiencing at that moment. There may be times when the person with dementia has an unrealistic expectation, misinterprets a situation, appears to be reliving a past event or, believes something is true that is not true. It is probably not the best strategy to try to bring the person back to our sense of reality by using logic or orienting him or her to time and place or by arguing. Connect, Refocus and Redirect might seem awkward at first, but with practice it becomes a simple technique that can be used to avoid arguments, confrontation and possibly catastrophic reactions.

Connect with the person emotionally

Let’s say you happen upon a resident who is very upset for a reason you believe to be unrealistic (she missed the bus, now she thinks she will be late for work). The unrealistic event is only unrealistic to us, but the emotion that provoked the delusion or the emotion associated with the unrealistic thinking is “real” to the resident. In order for us to connect with the resident, first, validate the underlying emotion that he or she is feeling. The person needs to hear that you recognize what they are feeling and understand why they feel that way.

Refocus the person’s attention

The second step is to “refocus” or, change the resident’s thinking to something different from his or her original intention.

Redirect to something different

The third step in the process is to “redirect”. This is where you give the person something very different to physically do with his or her hands, or something that demands some degree of attention. Using the example above, a resident is pacing in the lobby at 7:00 am saying that she is going to be late for work if the bus doesn’t come soon. You know that the person has been retired for years and that no bus comes to the building. Our natural tendency might be to explain that she is now retired and that she doesn’t have to worry about work any longer. To the resident, she is going to lose her job, and she will not be able to provide for her family. These are real emotions to her in that moment.

Connect Emotionally	Refocus	Redirect
<p>While standing in the lobby with the resident you could say:</p> <p>“I know how you feel. I get upset when the bus is late too. I wouldn’t want to lose my job. Come with me and we’ll look at the bus schedule to see when the next bus is coming.”</p>	<p>When walking with the resident to look for the bus schedule you could say:</p> <p>“Have you brought your lunch today?” Here she must think about something different. You can continue to move her away from her original intention of going to work by asking her to make decisions about what she will take for lunch.</p>	<p>As you are walking away from the lobby looking for the bus schedule, you could say:</p> <p>“Let’s check your refrigerator (or the kitchen if you have a dining program) to see what you have to make a sandwich for lunch.”</p>

Good communication techniques:

- Approach the person from the front
- Make eye contact
- Call the person by the name they prefer
- Tell them who you are
- Speak slowly and in short phrases
- Ask for what you want, not what you don't want (i.e. as Mary heads outside without a coat - Hi Mary, I'd like to show you something in my office, instead of "Don't go outside, you don't have a coat on").
- Use therapeutic fiblets (described below)
- One step directions
- Be mindful of volume, speed of speech, and keep content as simple as possible
- Limit distractions
- Show interest and be supportive
- Offer comfort and understanding by holding eye contact and nodding, or put your hand on the person's hand, arm or shoulder if appropriate
- Be patient and give time to respond
- Offer a guess if appropriate
- Allow them to repeat what they say
- Repeat yourself if necessary
- Use the five senses to connect with or calm the resident – does seeing, hearing, smelling, tasting or touching something positively affect the resident?
- Keep trying – failures lead to successes

Remember that the hippocampus is broken in the person with Alzheimer's, so the information they take in through hearing, seeing, touching and the other senses will not get stored, and they will not remember what you told them, such as "Wait here", "Don't go in there" or "Those clothes are dirty".

Joining Them in Their Reality

A good method of connecting with someone without short-term memory is joining them in their reality. Do not try to reorient the person to the here and now. If they believe they just saw someone you know to be deceased, ask "What was she wearing?" or "Tell me about your husband. What is he like?" If they insist it is time for breakfast at 4 p.m., ask what they would like to eat. That may lead to your helping them find something to eat, or it may lead to a conversation about favorite foods, recipes, or memorable dining experiences. Maybe the person wasn't hungry as much as confused, or maybe they really were hungry and needed your help. Most subsidized senior housing do not have "extra" staff; however, if a behavior is exhibited that needs attention, perhaps a resident service coordinator can step in, perhaps it prompts a call to a family member, support agency or an adult day health program.

Focus on the Feelings, Not on the Words

We know that Alzheimer's disease destroys the brain, but emotions remain (see the section on the Amygdala). People still feel emotions, are able to express emotions (sometimes non-verbally) and can sense the emotions of others. In order to help the resident get through a difficult emotion or behavior, focus on the feelings behind the words or actions. This will most likely be a familiar example, especially to the maintenance staff:

A resident comes to your office very angry or agitated and blames a maintenance worker for stealing something from her/his apartment such as the iron, black bras, a pair of slippers, jewelry, wallet... (all real examples from JCHE...). For this example, let's use the wallet. If we were to focus on the words, our natural response might be "Marianne, I know Tony very well and he wouldn't take your wallet. He's worked here for many years and has never stolen anything before." Instead of using reason, think about the item they are claiming is missing. What significance does that item hold? If it is the resident's wallet, what is in it? Is it a license, photographs, money, credit cards that the resident was looking for when they realized that they could not find the item (as opposed to when they realized the item had been stolen). They may not even remember what they were looking for, but they know it brought up feelings. In order to best help the resident, respond to those feelings. Say something like "Oh, sure you are upset. I would be too if my wallet was missing. Let's see if we can find it together." The cognitively impaired resident may not even realize the significance of the item. Does their license tell them who they are, what they look like, or where they live? Do pictures of their family remind them to whom they belong? Look for the emotion beneath the words – is she really telling us she has lost her sense of self.

Using all of the techniques thus far, see the chart below for some suggested language.

Resident's behavior	What <i>not to do or say</i>:	What <i>to do or say</i>:
I want to go home right now!	<p>Do not reason or explain:</p> <p>“You’re already home.”</p> <p>”You can’t go home because your house was sold and you live here now.”</p> <p>“How are you going to get there anyway, you don’t have a car anymore, remember?”</p>	<p>Depending on the resident’s level of distress and dementia, ask “Can I help you?” Use a therapeutic fiblet:</p> <p>“Let me check with your daughter to see what time she is coming (or the cab, or the bus) and I will get right back to you. In the meanwhile I think I hear someone playing the piano in the community room.”</p> <p>Connect and redirect the person:</p> <p>“I heard about your home and that it is very cozy. What do you like most about your house? Is there land around it? Is that where your kids were raised? It is just about lunch time, are you hungry? I’m thinking about what I had for dinner last night and how good it was. What is your favorite meal?”</p> <p>Ask for their help with a small task – “Before you go home, would you be able to help me sort these papers on my desk?” “Could you help me fold these papers and stuff these envelopes? Could you help me staple these sheets?”</p>
Resident is sitting in the lobby crying or yelling.	<p>Do not ignore or deny their feelings (fear, sorrow, anger).</p> <p>There’s nothing to be afraid of, stop yelling!</p> <p>“Stop crying, everything is fine.”</p>	<p>“Oh Mary, I can see how sad you are. I’m so sorry you are upset. Let’s sit down and talk because I want to hear what is bothering you.”</p>
Resident is in the hallway very agitated, saying “No, it’s wrong, it’s all wrong”.	<p>Do not say things like “relax”, “calm down”, “everything is fine.”</p>	<p>“Joe, I can hear how upset you are. I’m so sorry you are feeling so angry. Let’s go into my office, maybe I can help.”</p>
“I know you stole my wallet!”	<p>Do not take what is said personally.</p> <p>“No I didn’t. I’m a very honest person; I would never take what wasn’t mine.”</p> <p>“I make a lot more money than you do. I don’t need what’s in your wallet.”</p>	<p>“What is in your wallet that you are looking for? Maybe we can look together and see if we can find it.”</p> <p>“Let’s take a look in your apartment. I think I remember seeing it in your pants pocket yesterday.”</p>
“My mother is coming to pick me up to take me to the dentist.”	<p>Do not point out or correct misstatements.</p> <p>“Since your mother has probably been dead for a long time, I think you might mean your daughter”</p>	<p>“Oh, is this a regular check-up, or is there something wrong?”</p>

Resident's behavior	What <i>not</i> to do:	What <i>to</i> do:
The resident is just about to walk into the wrong apartment or an office or into a staff meeting, or helping themselves to refreshments put out for a special event...	<p>Try very hard not to use the word "No".</p> <p>"No, don't go in there."</p> <p>"No, leave those alone, they are not for you."</p>	<p>Keep in mind that the resident will likely not remember that they have dementia. They will only think you are harsh for speaking to them in an unkind manner.</p> <p>"Sarah, can I help you find someone?"</p> <p>"Gladys, doesn't that pastry look good? They are for the entertainer we are having in a little while. I hope to see you there."</p>
"I want that store to come into my room, and then it's not."	<p>Do not expect what is said to make sense or be correct (word salad).</p> <p>"Sam, I have no idea what you are trying to say to me. Why don't you go back to your apartment and think about it."</p>	<p>Try to figure out what the person means. If you can't, make eye contact and nod. Be patient, offer a guess, and realize how frustrating it is for the person.</p>
"I I have..... to....."	<p>Do not get frustrated in front of them.</p> <p>"George, get it out! I don't have time right now to sit here while you finish your thought."</p>	<p>Patience is the key!!!!</p> <p>Again, take the time to realize how difficult it is for the person. Make eye contact, be patient. If you cannot spend any more time with that resident, politely excuse yourself, or have another person take your place.</p>
"....."	<p>Do not stop talking to someone who is no longer able to talk.</p>	<p>"Good morning, Faina. It looks like a beautiful day. I hear it will rain tomorrow. I'm looking forward to the flowers coming out. I'll see you tomorrow."</p>
You see a resident heading outside without a coat on a cold day.	<p>Try not to startle or embarrass the person.</p> <p>"Stop! It's too cold to go out without a coat. Come back in before you freeze."</p>	<p>"Hi Mary, can I ask you something before you head out? Since it is kind of private, let's go to your apartment or my office." On the walk you have time to think of what to tell or ask her once you get there. If you can see she is determined to go out, say "Oh, let's get a coat for you because it is quite cold out and I don't want you to get sick."</p>
Resident has on the same outfit for many days in a row.	<p>"Bella, how about we wash those clothes. You've been in them for too long, you smell bad, and other residents are complaining."</p>	<p>Best to be in touch with a personal care homemaker, case worker or family. There are special ways to encourage a resident to bathe or change her/his clothes. Find something that matters to the resident.</p> <p>"Bella, I think your daughter is coming to pick you up later. We better get changed so you are ready for her."</p>

4. Purposeful Engagement (Activities, Social Engagement, Building a Sense of Purpose)

Keeping people with dementia involved, engaged, active, and having a daily agenda is one of the most challenging problems in independent housing. As stated early on – senior housing, especially federally, locally or municipally funded, doesn't usually have the money to support the level of staffing required to properly care for a population of significantly impaired residents. And again, that having been acknowledged, they are our residents, and they will likely not die or move into a nursing home on our schedule.

Most challenging symptoms associated with Alzheimer's disease are caused because residents become depressed, withdrawn, and shunned by the cognitively intact residents. Social isolation and loss of status among peers can cause agitation, anxiety, paranoia, disorientation, depression, anger, disinhibition, wandering, loss of appetite, sleep disturbance, etc. Finding ways to keep the person engaged in activities is a critical piece in our efforts to keep the person in senior housing longer... even if only for a few more months.

Housing staff could seek assistance from clergy. Many religious or community organizations have ministries or volunteers that work with elders and some organizations have specially trained "friendly visitors" who work with elders with dementia. If the person is religious, it is important that they remain involved in religious celebrations and services. Some senior housing programs have developed a friendly visitor program, which invites residents and family members to serve as "friends" to those with dementia or suspected dementia. Some facilities have small group sensitivity training around disabilities, including dementia in the training as a disability. It is best to do this in small groups led by an experienced facilitator. By including dementia among many other disabilities like hearing loss, visual loss, mobility loss, it reduces the stigma associated with "going senile" and gives other residents a greater understanding that Alzheimer's is a disease and not under the person's control. Check with your local Alzheimer's Association to see if there is a program in your area.

It is important that the resident stay engaged as much as possible with family and friends, and participate in family and other events as appropriate. You may consider having children and grandchildren set up a regular visiting schedule to give the resident an agenda for the day, something to look forward to.

If the resident is new to your building, a good sense of his or her personal history might help in planning what activities that would interest them (see Knowing and Understanding the Resident). It can be helpful if a resident actually invites the new resident to participate in the activity for the first time and escort her to the activity and make her feel welcome. Almost all challenging behaviors that cause a person to leave senior housing prematurely are caused by the lack of meaningful activities available over the course of the day and early evening.

Tips for Keeping the Person Socially Engaged

- Have family/friends provide you with a good personal history of the resident and ask about how the resident was engaged in social activity previously
- You might have a monthly new resident welcoming party
- Encourage family to make links with local agencies and programs like the Senior Center, the Adult Day Health Program, the Social Day program, local religious organizations, Friendly Visitor Organizations, Alzheimer's Association Chapter etc.
- Form an in-house "Buddy" program with training for volunteer buddies
- Work on ways to change the "culture" of your building so that residents don't shun those with cognitive impairment
- If you have the staff and financial resources - plan regular community outings, and if you do not have the resources, build partnerships with community organizations that can help you with community outings like the Council on Aging or the Area Agency on Aging
- In order to get a reluctant resident to participate in the social event, you might say that the staff could use the resident's help in setting things up or, help with the folks in wheelchairs is needed. In other words, they are not really participating, but more there as a helper
- Keep in mind that any housekeeping task can be made into a meaningful activity
- Establish resident-run clubs so residents have something to do: a walking club, a current events club, a graphic arts club, an audio book club, a gourmet tasting club, a handcrafts club, a virtual European tour club, a poetry club, a men's club, a chess club, a puzzle club, and so on

Case Example

Sylvia is a 79 year old widow who moved to the community three years ago from California after her husband passed away. She has several children and grandchildren nearby who visit her often. Sylvia's behavior demonstrates short term memory loss, difficulty following directions, hygiene issues (especially around changing her clothing) and personality changes.

Sylvia often comes to the front desk, asking about activities, especially bingo – up to 20 times a day, or complaining that she is bored, even though she just spent the hour before in a music group or exercise class. She also becomes increasingly agitated when there is a change in the posted schedule.

This has been very challenging for our staff and volunteers (who are either from the local community or residents themselves) because the community does not have enough people to work with her one-to-one. To promote a sense of purposeful engagement, we asked Sylvia if she would be willing to help us by cutting coupons from the Sunday paper that would be shared with other residents, or cut out pretty pictures from magazines that we will use to make into a collage. Even if there was no collage to be made, we might use a fidget such as: we were asked by a local elementary school if we could provide them with these pretty pictures for the students' art projects. Whatever would give the resident a sense of purpose is what we try to create.

So you may be sitting there reading this thinking “Neither I nor other members of the staff have time to do these things”! Remember that every task can be an activity, regardless of your role or your level of interaction with the resident.

When maintenance staff has to visit Sylvia's apartment to change a filter or accomplish another task, she becomes very agitated and paranoid. The maintenance staff take a few minutes to establish a connection with Sylvia (see spend 5 to save 20), and again, by enacting the concept of purposeful engagement, the maintenance staff bring a roll of duct tape or other safe product, and ask her to hold it while they accomplish their task. They may even ask her for a piece to keep her engaged in the activity.

Many of our residents see their neighbors with more advanced dementia attend our adult day health program, and find it scary. For these residents, we have also begun to keep brain strengthening exercises at our front desk – things like crossword puzzles, word finds and Sudoku games that any of our residents can use to keep their minds active. We have found that keeping these brain strengthening activities at our desk has not only led to decreased complaints of boredom by those folks who have some symptoms of dementia, but also has allowed those who are afraid of ‘getting dementia’ feel that they are being proactive in staving off the symptoms.

5. The Resident's Behavior as Their Way of Communicating with Us

The resident's verbal and non-verbal communication can tell us how they feel physically and/or emotionally. We now realize that many symptoms or behaviors associated with Alzheimer's disease are caused by the resident's problems and frustrations with the physical environment or caused by events that we can control. In some cases, dramatic changes in behavior may be caused by an internal trigger - like dehydration, infection, depression, pain, a slight but chronic irritation like dentures that are ill fitting. The important point is that once you understand the underlying cause of the behavior, you can plan an intervention to eliminate or control the behavior.

Some Important Points About Behavior

- All challenging behaviors are caused by something. They are not random events
- All challenging behaviors caused by Alzheimer's disease-based changes in the brain are expressed through an existing personality
- All challenging behaviors are caused by either internal or external triggers
- Understanding the triggering condition or event enables you to plan interventions that control the triggers and therefore the behavior
- We cannot blame the person for the behavior
- Behavior is a form of communication, that is, the behavior is telling us that something is wrong
- Behaviors can be classified in terms of their significance:
 - As a nuisance
 - Socially inappropriate
 - Behavior that affects the well-being of others
 - Behavior that is a general health risk to self or others
 - Behavior representing a danger to self and others
 - Behavior that is an immediate danger

Triggers

Again, the behavior of a cognitively impaired person is their way of communicating. Is everything okay, or is something wrong that needs to be addressed? There are two types of triggers or causes for behavior: internal and external. An internal trigger is something happening in the mind or body of the person. An external trigger is something that is happening around them or to them.

Our natural tendency is to assume that everyone is in complete control of their behavior and it is difficult to understand how some people who are in the earlier stages Alzheimer's disease may behave in uncharacteristic or bizarre ways and we tend to hold them responsible or expect that it is within their capacity to change their behavior. The person with dementia is often very good at reading our emotions and senses our insensitivity to their situation. It is important that staff, and particularly other residents, understand that the uncharacteristic behaviors the person with dementia may now be exhibiting are caused by her/his disease and not within her/his control. Holding them responsible leads to shame, which can worsen the of behavior.

Case Example of an Internal Trigger

A resident reported to the office that her 82 year old neighbor knocked on her door in the middle of the night saying that there was a strange man in her bed and she wanted the police to come and remove him. The neighbor did not know what to do and sent the resident back to her apartment scared and frustrated. The next morning, the neighbor reported the incident to the resident service coordinator, who checked in with the resident. Using the Basic Assessment Skills she had learned, her interview with the resident revealed that something was indeed wrong. She contacted the resident's daughter, who took her mother to the physician. The resident was found to have a urinary tract infection (UTI) that caused her mother to become even more disoriented.

This behavior had an internal trigger, namely the infection, which caused the exacerbated confusion. Although, the behavior could be classified as one that affects the peaceful enjoyment of others, it was seen by management as controllable and limited in nature.

Behaviors caused by internal triggers generally appear relatively quickly and may be "organic" (due to a medical reason). Look for these symptoms of "internal triggers":

- Irritability
- Lowered tolerance to frustration or noise
- Paranoia
- Hallucinations or delusions
- Anxiety
- Aggressive behavior or sexually aggressive behavior
- Increased confusion and disorientation
- Restless sleep
- Changes in appetite
- Sweating

Usually these behaviors require quick attention to the medical source and often require medications over a period of time.

Case Example of an External Trigger

A man in middle stage Alzheimer's disease occasionally yelled at other residents, but the reason was not apparent. The staff observed the situation using a behavior log (see below for description of Behavior Log and Appendix for the log itself) where they recorded **what** happened, **when** it happened, **where** it happened, **who** was around when it happened, and **what** happened just prior to the behavior. The log revealed that he only yelled at people during the day, in the community room when he was seated on one side of the room and not on the other side of the room. Careful observation revealed that when the resident in question was seated on one side of the community room, the light coming in through the windows across from him was in his eyes, and he walked

Trigger	Internal or External
He is hungry	Internal
The room is too hot	External
He is constipated	Internal
She has a toothache	Internal
She has nothing to do	External
The room is crowded and loud	External

across the room to the person sitting under that window and yelled at them. Once we identified the trigger, all we needed to control the behavior was to simply close the blinds on that window. The resident's behavior was a form of communication. His behavior was telling us that something wasn't right; in this case, the sun was in his eyes.

Changes in mood and behavior that come on more gradually are more often caused by something we are doing, or not doing, or by something in the physical environment that the resident cannot master, control, or understand. Usually these behaviors have a trigger that we can control, and hence change or better manage the behavior. Sometimes, it may take sometime to figure out what is causing a certain behavior. Most of the time, nothing very bad happens; however, sometimes a resident is feeling so much emotion that they can not control, that they exhibit a "problem behavior".

Problem Behaviors

We know that people with Alzheimer's and other forms of dementia sometimes behave in odd or troubling ways. We may not understand the behavior. It may take us some time to figure out the trigger and if one of the Habilitation domains could alleviate the resident's distress. Problem behaviors however, must be addressed immediately. A problem behavior is one that poses a health or safety risk for the person with dementia, a staff person, or anyone else. One must also ask for who is the behavior a problem? Take a look at these examples:

Behavior	Problem Behavior?
Wearing mismatched clothes	No
Asking the same question over and over	No
Pacing or wandering	Maybe
Refusing a bath or shower	Maybe
Tries to hit you	Yes

The first two are pretty obvious, wearing mismatched clothes and repeating a question does not put the resident or anyone else in danger. The next two examples could go either way: Is the resident pacing or wandering in the hallways or an activity space (safe)? Or, is the resident wandering outdoors? Is the weather conducive to outdoor activity? Is anyone accompanying the resident? Is there ice on the ground or is the resident heading toward a freshly

washed slippery floor (unsafe)? The same is true about refusing to bathe. Not bathing or bathing infrequently may not be an issue for the resident. They may do a short sponge bath, which is sufficient. But they may also have other issues such as skin or other infections that require cleaning on a more thorough and frequent basis. They may also have an odor that is bothersome to other residents, guests and staff. Finally, behavior that is clearly a problem is any sort of physical violence.

Knowing what to do when health or safety are at risk takes level headedness and practice. Review these steps frequently and practice them with other staff members. A problem behavior can get resolved quickly and easily with the right intervention.

What to do when behavior poses an immediate risk:

They are going to hit or have already hit you:

- Do not hit back
- Step back and get out of their reach
- Say something like, "That hurt."; "It hurts when you hit me." "Ouch! You slapped me."
- Keep calm and do not raise your voice
- Connect with their feeling, not their actions
- If possible get help
- If safe, leave them alone for a short while or redirect them to another activity

They are going to hit or have already hit someone else:

- Calmly get their attention on you so they stop advancing
- Say something like, "Stop Joe."; or "It hurts when you hit, slap, kick, etc."
- Respond to their feeling, not their words or actions
- Reassure and calm them
- Look to see if their body language shows they are relaxing
- Connect with them and redirect them away from the other person

They are doing something that is a potential danger to themselves or others:

- Calmly get their attention
- Connect with them, engage them in general conversation
- Redirect them to another activity
- Casually attempt to take the dangerous item ("Joe, can I help you with that?")
- Escort them away from the unsafe area

It is critically important to know what to do in case of emergency – but not all behavior, even problem behavior, is an emergency. Before we understood Alzheimer’s disease, a problem behavior may have prompted a call to 911, often an unnecessary and confusing trip to the emergency room for the person with dementia, and disruption for the person’s family. Now we are able to apply the concepts of Habilitation Therapy to communicate effectively and appropriately with the resident, create physical environments that compensate for their losses, provide opportunities to engage them in purposeful activity, and understand how the resident’s behavior is their way of communicating with us. But how do we get from theory to practice?

Establishing Behavior Teams

Certain categories or classifications of resident behaviors are behaviors that are inconsequential. There are mere nuisances i.e., Mrs. Jones wears mismatched clothing. Wearing mismatched clothing is uncharacteristic of Mrs. Jones prior to her dementia, but in the scheme of things, it is not a serious problem. There are other manifestations of behavior that may be a problem for the person with dementia or a problem for others in your community. Most of these problematic behaviors can be modified, managed or eliminated altogether when you create a team to determine what the underlying triggers of the behavior might be, and then, to develop a plan of action to address the internal or external triggers and ultimately control the behavior and its effects on your community. We encourage the formation of behavior teams made up of three to five members who meet regularly to evaluate resident behaviors and develop behavioral plans when needed. The team approach increases the level of insight into the origins of the behavior and the creativity of the behavioral plan. A team, as opposed to a single individual, allows for more people to manage the behavioral plan. The team can be made up of key staff from various departments, outside consultants (nurses, social workers, homecare providers, service coordinators, clergy, retired volunteers from the community) and family members. Try to get permission from the family to discuss a resident using identifying information. If no permission is given, use non-identifying information.

The behavior team should consider:

- Describe the behavior in detail (Example, John yells)
- Statement of the problem (because John yells, others are frightened)
- Observed patterns of the behavior (when, where, who was around)
- Are the triggers to the behavior internal or external
- The teams hypothesis as to what is causing the behavior (John needs something to do in the afternoon)
- The intervention plan to control the behavior (engage John in a project each day at the that time)
- The expected outcome or goals of the intervention (John will stop yelling)
- State how long the intervention plan will be in effect (until John’s disease progresses to the next stage)
- Who will manage the implementation of the intervention plan (the RSC)

Often thoughtful behavioral intervention planning can avoid premature eviction of a resident with dementia. However, there are certain behaviors, typically those that are related to the resident’s inability to care for themselves or uncontrollable problem behavior that might require a move to a skilled care facility.

Either we are doing something wrong, the environment is confusing, disorienting, overstimulating or misperceived, or there is a medical or physical problem that is causing the person to behave in an uncharacteristic way.

Case Example

Mrs. K. was diagnosed with Alzheimer’s disease 5 years ago. Initially, Mrs. K. had a problem with remembering appointments and scheduled activities. Family installed a large white board calendar and each week they wrote in important appointments and activities that Mrs. K. was able to follow.

Some months later Mrs. K. had a series of incidents where she left pots of food on the stove unattended and caused smoke detectors to alarm. After an agreement was reached with the family, the housing staff disconnected the stove and Mrs. K. was

enrolled in the Home Delivered Meals program.

Three months later Mrs. K. experienced problems with her personal care. Because Mrs. K. had some money in the bank, she was not eligible for state-funded home care services, and her family contracted a private homecare agency to assist Mrs. K. with showering twice a week. After some initial resistance to the personal care Mrs. K. accepted the aide's assistance. Two months later Mrs. K. went out of the residence unattended, became lost and was missing for several hours. She was returned to the community by the police.

The behavior team discussed Mrs. K.'s case and recommended that she attend an adult day health program five days per week and that the family provides supervision on the sixth and seventh days. A home health aide came in the evenings to assist Mrs. K. with getting ready for bed.

This plan worked for several months, until Mrs. K. was up at night knocking on other resident's doors asking them where her husband was. The nurse at the adult day health program contacted Mrs. K.'s doctor and they determined the presence of a urinary tract infection (UTI) that was the likely cause of the nighttime confusion and disorientation. After the first few days on an antibiotic, the behavior changed and Mrs. K. slept through the night. Three years after her diagnosis, Mrs. K. became financially eligible for home care services.

As the disease progressed, she developed significant problems with walking and required the use of a walker, and later, a wheelchair. It was only when Mrs. K. required assistance from bed to chair that the family could no longer manage her home care services and arranged for a nursing home placement.

Mrs. K. was able to remain in her home with assistance, thoughtful planning and coordination of care for several years longer than she might have otherwise.

Behavior Log: Sleuthing the What, Where, When, Who and Whys of Behavior

A behavior log is simply a tool that can help map out patterns in behavior and help staff understand what

the behavior is telling us about the resident's needs. Ideally, the log can help record a number of different pieces of information. When the person demonstrates a challenging behavior try to describe and record the behavior objectively in some degree of detail, all of which may be very important:

- Exactly "**what**" happened, how the person looked, his or her body language, tone of voice, etc.
- Exactly "**when**" the behavior took place (time and date)
- Indicate "**who**" was in the area when the behavior took place and how these persons were involved or reacted to the behavior
- Describe exactly "**where**" the behavior took place

The disease is to blame for the behavior, not the person.

Eventually, all this information may help you understand the triggers to the behavior or in other words, the "**why**" of the behavior.

Again, we found that working as a team helped us put together the pieces of the behavior puzzle, and that team may include RSC, administrative staff, maintenance, and even other residents.

Behaviors are not random. Behavior, as we said earlier, is a form of communication, telling something about the person's well-being or, lack of it when the resident is unable to understand or articulate that something is wrong. Either we are doing something wrong, the environment around the resident is confusing, disorienting, over stimulating or misperceived or, there is a medical or physical problem that is causing the person to behave in an uncharacteristic way. We always have to ask ourselves is this the way the person would have reacted or behaved before his or her illness? We may or may not be able to answer the question, but we still have to ask. The disease is to blame for the behavior, not the person, and the log helps us better understand how the illness effects the resident view of the world and his or her ability to negotiate in that world with an impaired brain.

The log can be used in several ways. First, it can be used to observe the behavior over time. Recording the behavior over several occurrences in order to get a fuller understanding of the underlying patterns of the behavior has proven to be very useful. For example, you record seven instances that Mr. Jones wanders the corridors in the building in the late afternoons

and is discourteous to the other residents he passes along the way. He never sees the same people in these instances. He never takes the same route on his wandering episodes. He never wanders when he is engaged in an activity in the afternoon. The identification of patterned behavior can help think about the underlying causes of the behavior and plan an intervention. So, multiple chartings of behaviors as each behavior occurs using the log is one important use. Another use of the behavior log is to determine if an intervention that you have in place is working. So in our example above, if we hypothesized from the information gained in the log that Mr. Jones wanders in the late afternoon, because he is bored and looking for something interesting to do, we might have him engaged in activities that we know he enjoys and use the log to see if he wanders during those days when he is actively involved in an activity.

We've established that the behavior log captures the behavior: "the what"; "the when"; "the where"; and "the who", and that it can reveal "the why" of behavior. The log can also be used to show if our intervention to change the behavior is working, and whether the behavior is so significant that the resident is a danger to her/himself or to other residents. The log in this type of situation can serve as documentation that resident requires supervision beyond what can be provided in independent housing, even with the available supports, and be part of the documentation required for the eviction process.

Summary

This guide has outlined the concepts behind the Habilitation model and provided practical steps to interact with cognitively impaired people, as well as how to adjust the environment around the person and his/her needs.

Utilizing this model requires a shift in thinking from strictly managing housing, to creating an environment where our memory impaired residents can continue to age in their apartments with our assistance, if only for a few more months or even for years.

To restate, the goals of Habilitation are:

- Promote a positive emotion
- Maximize the remaining skills and abilities
- Minimize the limitations

The five areas or domains of the Habilitation model that can be used to achieve these goals are:

1. Knowing and Understanding the Individual
2. The Physical Environment
3. Our Communication with the Resident
4. Purposeful Engagement
5. The Resident's Communication with Us

We sincerely hope that you find this guide helpful when working with cognitively impaired residents. Keep trying and good luck.

