Chapter 31

# A Married Couple Dealing With Alzheimer's Disease

Carolyn M. Baum, PhD, OTR/C, FAOTA

## Introduction

Alzheimer's disease robs the mind of its capacity to make decisions and carry out activities that define the individual. OT offers a client-centered, occupational performance-oriented approach to the person and family as they build the strategies to live their lives. This chapter will provide information for the OTA to employ with persons with cognitive loss, and although it will focus on Alzheimer's disease, the strategies presented will be helpful in interacting with clients or patients who are experiencing cognitive problems or cognitive decline (e.g., multiple sclerosis, Parkinson's disease, stroke, head injury, schizophrenia, and learning disabilities).

Dementia of the Alzheimer's type (DAT) is a progressive, degenerative, and devastating disease for which there is no cure. The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (American Psychiatric Association, 2013) characterizes DAT by memory loss, impaired abstract thought and judgment, and abnormalities in higher cortical function with resulting personality changes. As it progresses, the disease increases impairment in cognitive function, reflected in deterioration of the ability of the individual to perform tasks and interact socially with family and others.

For centuries, senility was viewed as an inevitable consequence of old age. Doctors have applied the medical diagnosis of DAT since the 1970s (Ramsdell, Rothrock, Ward, & Volk, 1990). The search for a cure has spurred families overwhelmed by the consequences of the disease to demand action from Congress, which responded by allocating monies for research and services (Fox, 1989). Generally, 7.5% of the population over 65 have DAT (Gurland, 1985). The prevalence rises to over 20% in individuals over the age of 80 (Magaziner, 1989). Twenty percent of our seniors suffer from some disability that affects function (Alzheimer's Association, 2004; American Association of Retired Persons, 2002) and establishes DAT as a major societal problem.

The family, as the primary caregiver, is faced with the functional, behavioral, and neurological problems of the person with DAT, often without having access to treatment because DAT is not a diagnosis that requires acute medical intervention, therefore, they and their families are not given access to many institutional-based rehabilitative services. Community programs must emerge to help families learn to manage the problems associated with neurological deficits.

Cognitively impaired persons experience anxiety and display disrupting behaviors that may be related to their diminished ability to process information to perform instrumental, self-care, and social activities. Such behaviors may be indications that the person with cognitive loss is bored or not able to do what he or she wants or needs to do. It can be posited that if the caregiver can set up and support the environment to keep the impaired person engaged in a routine of activities, the effort could potentially minimize the

Sladyk, K. (Ed.). *Ryan's Occupational Therapy Assistant: Principles, Practice Issues, and Techniques* (5th ed., pp. 426-441).

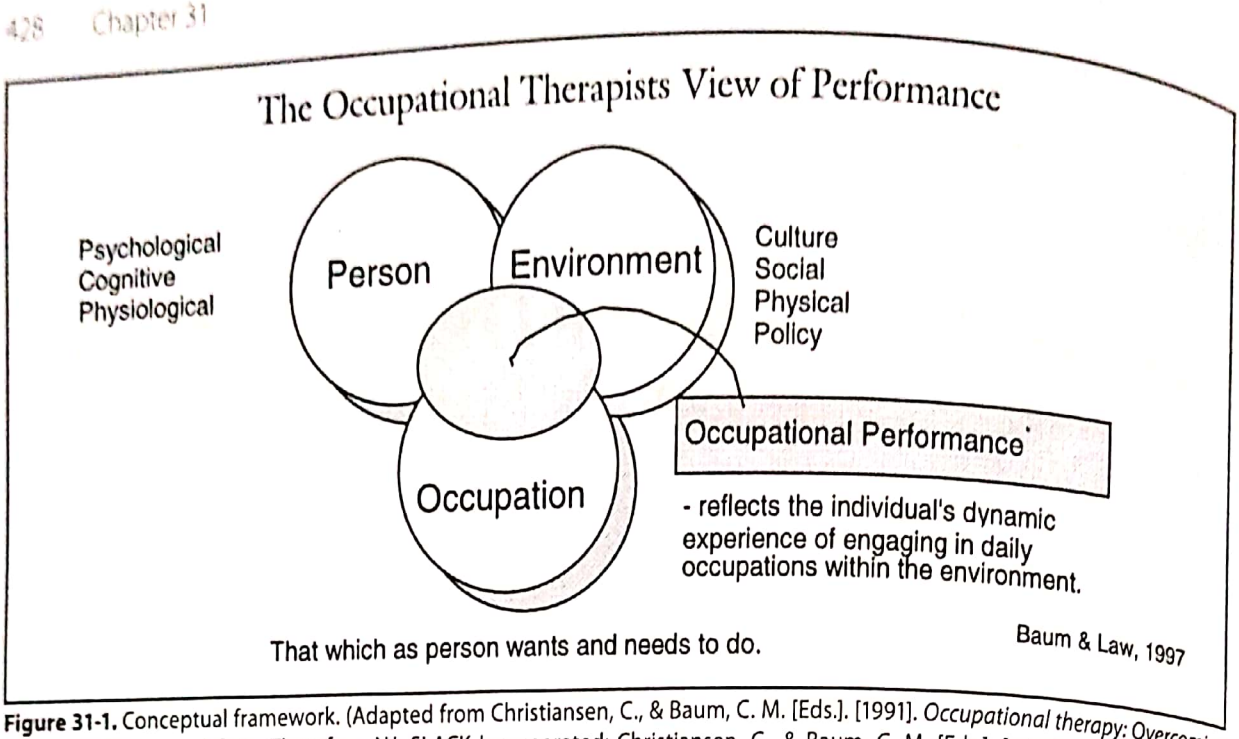


**Figure 31-1.** Conceptual framework. (Adapted from Christiansen, C., & Baum, C. M. [Eds.]. [1991]. *Occupational therapy: Overcoming human performance deficits*. Thorofare, NJ: SLACK Incorporated; Christiansen, C., & Baum, C. M. [Eds.]. [1997]. *Occupational therapy: Enabling function and well-being*. Thorofare, NJ: SLACK Incorporated; and Law, M., Cooper, B., Strong, S., Rigby, P., & Letts, L. [1996]. The person-environment-occupation model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy, 63*, 9-23.)

disruptive behaviors of his or her loved one and reduce his or her stress.

OTs and OTAs play a critical role in helping families acquire the knowledge and skills to support their loved one's behavior as they strive to maintain dignity and engage in activities. There is consensus that activity is important to maintain cognitive and physical health (Almli, 1993; Christiansen, 1991; Fidler & Fidler, 1963; Kielhofner, 1992; Lawton, 1990).

## Alzheimer's Disease and Its Functional Progression

The brain processes information and organizes behavior. In DAT, the brain atrophies and loses functional connections, which impairs the nervous system's ability to process the sensory information it receives from the environment. Persons with DAT often have primary sensory impairments (visual, olfactory, gustatory, auditory) because the key centers of the brain that interpret information do not allow the person to create appropriate responses. This means that his or her vision, taste, smell, and hearing may be impaired, complicating his or her ability to participate with others.

Cognition is the process by which sensory input is transformed, reduced, elaborated, stored, recovered, and used (Duchek, 1991). Since behavior is dependent on sensory input, DAT interferes with the individual's performance. As the disease progresses, the individual with DAT becomes unable to process information. People experience losses in their ability to access memory, use language, and perform motor acts (Baum, Edwards, Leavitt, Grant, & Deuel, 1988). The loss is demonstrated when the person has trouble carrying out tasks of daily living and interacting socially. He or she also has difficulty in solving problems (Baum, Edwards, & Morrow-Howell, 1993; Edwards & Baum, 1990).

DAT has been thought to be a deficit of memory. Memory is a problem, however, and individuals can exhibit many different neurological deficits. These deficits are not always present, and if they are present, they may be displayed differently in different stages of the disease. This means that a person with DAT requires accurate assessment to determine the extent of the deficit and how it contributes to the person's occupational performance.

People with Alzheimer's disease may display the following:

- They may not be able to discriminate facial expression or voice tone qualities (Allender & Kaszniak, 1989; Eslinger & Damasio, 1986). This can explain why people have difficulty recognizing staff and family. If someone were to change his or her glasses or hair color or style, the person with DAT would not be able to recognize him or her.
- Aphasia may limit or obscure the person's ability to comprehend or express language (Faber-Langendoen et al., 1988). Just because someone cannot speak, it does not mean he or she cannot communicate. A speech pathologist can help identify successful strategies, such as having the person read. Some people have difficulty

**Table 31-1**
**The Occupational Performance Assessment**

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|---|---|
| *Person factors* | The Kitchen Task Assessment (Baum & Edwards, 1993)<br>The Functional Behavior Profile (Baum & Edwards, 2000; Baum et al., 1993) |
| *Occupation factors* | The Activity Card Sort (Baum, 1993; Baum & Edwards, 2001) |
| *Environment factors* | The Memory and Behavior Problems Checklist (Zarit & Anthony, 1986)<br>The Zarit Burden Interview (Zarit & Anthony, 1986) |

initiating speech, and sometimes just starting a story will help them speak.

- Agnosia is an even greater difficulty for families because a person's inability to recognize objects and/or people is impaired (Mendez, Mendez, Martin, Smyth, & Whitehouse, 1990). People who cannot recognize objects need labels on the items and need a helper to be sure they have the right tool for the task they are trying to accomplish.
- Organized or purposeful movements are often difficult due to apraxia (Edwards, Baum, & Deuel, 1991). Families have great difficulty with apraxia, not understanding how the person can do some things and not others. Families sometimes think persons with apraxia are willful and difficult until they understand that the inability to move is a brain deficit.
- Impairment also exists in problem solving, judgment, organization, and sequencing due to frontal and temporal lobe damage (Baum & Edwards, 1993; Sullivan, Sagar, Gabrieli, Corkin, & Growdon, 1989). These functions are basic to people who are able to engage in activities. When these deficits exist, the person needs a caregiver who can get him or her started on tasks.
- Memory is affected in persons with DAT. Short-term memory is the memory that holds recent events prior to the event being stored. Persons with DAT cannot retain items in short-term memory. This is why you never want to ask a person with DAT "What did you have for breakfast?", "Was your daughter here this morning?", or "What did the announcer say about the weather?"
- Long-term memory is more complex; it can also be used if you can figure out strategies to tap it. Episodic memory is memory for personal episodes or events that have contextual reference. You can often trigger episodic memory with stories, pictures, and smells. Semantic memory is the memory for facts. It is difficult to tap semantic memory unless the person has extensively used information in their daily life. Some persons retain information about birds, flowers, or other categories of knowledge. Declarative memory is memory for general knowledge and is not often preserved. Prospective memory is the memory that we use to remember what to do. This is impaired in DAT, yet it is amenable to adaptive strategies and cues. The final type of long-term memory is procedural memory. This type of memory is knowing how to do something. We most often think of procedural memory when we think about how we know how to ride a bike, even though we have not done it since childhood. If we know what the person has done in the past, we can tap his or her procedural memory to perform tasks and activities that he or she could not do if it required new learning.

# A Framework for Assessment

## Occupational Therapy Evaluation

Information to frame treatment must be collected from both the person with the impairment and the caregiver. Because treatment involves training of the caregiver to construct opportunities for the person to stay engaged in occupational tasks, it is important to have a clear picture of the pattern of the person's deficits, a history of interests and activities, and the expectations and skills of the caregiver. Table 31-1 presents a model to guide the assessment process. Each of the instruments included in the model is described below.

The Kitchen Task Assessment (KTA; Baum & Edwards, 1993) requires the person with DAT to make a cooked pudding from a mix. It allows the clinician to administer a standardized measure without employing an artificial task. The KTA is a valid and reliable measure that can be used as a clinical as well as a research tool because it discriminates the performance of individuals across all stages of the disease. It records changes in the person's performance in initiation, organization, sequencing, incorporation of all steps, safety and judgment, and task completion. The information gained from the administration of the KTA can be used by the clinician to train the caregiver to assist the impaired individual in daily living tasks. The person must be directly observed in the performance of the task. The test takes approximately 15 minutes.

The Functional Behavior Profile (FBP; Baum & Edwards, 2000; Baum et al., 1993) is a reliable and valid

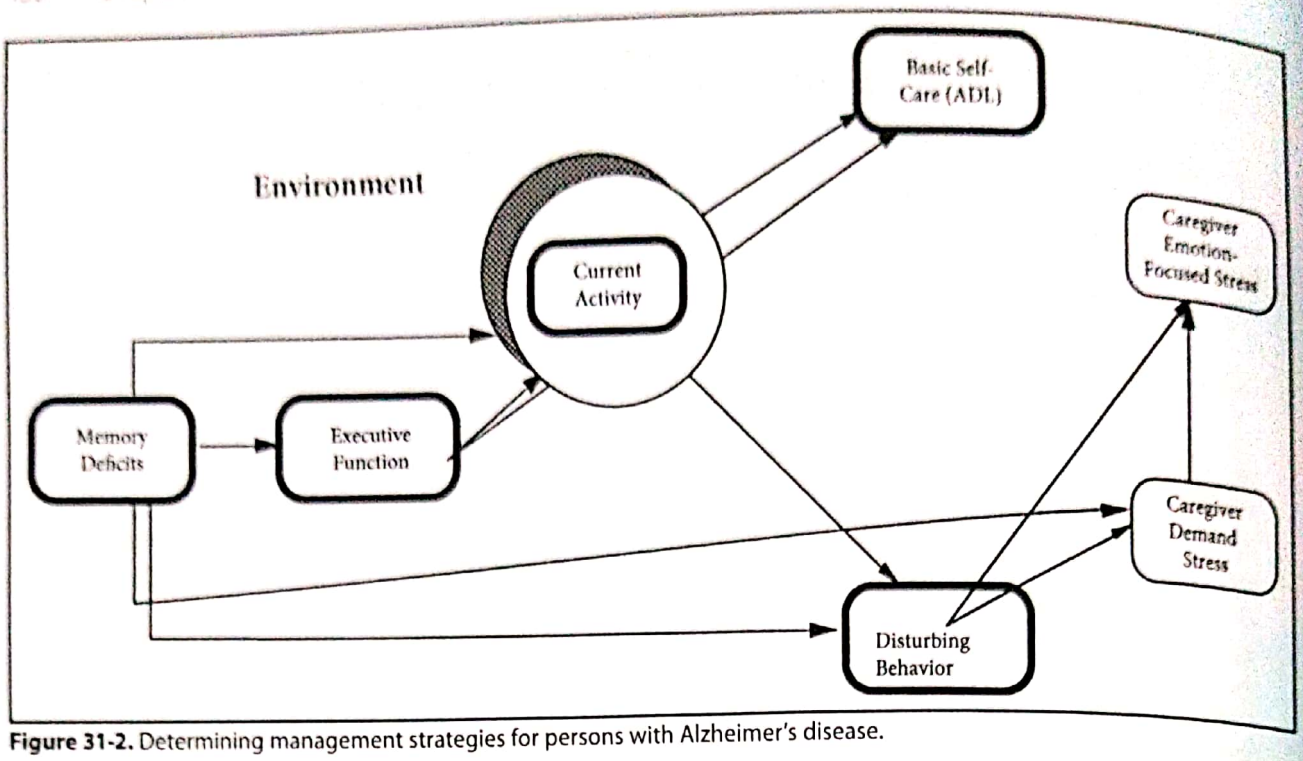


**Figure 31-2.** Determining management strategies for persons with Alzheimer's disease.

assessment that documents the caregiver's observation of the task, social, and problem-solving behaviors of a person with DAT. The FBP can help the caregiver focus on the presence of productive behaviors useful in managing the impaired person. When used with the KTA, it helps the clinician understand how the caregiver sees the capabilities of the person with the impairment and how that might differ from the responses that the therapist can elicit from the impaired person with the appropriate level of cueing. It can be completed in checklist or interview format.

The Activity Card Sort (ACS; Baum, 1993; Baum & Edwards, 2001) is a card sort of 61 activities including 13 instrumental, 36 leisure, and 12 social activities identified by older adults as activities they typically do. Using this assessment, it is possible to calculate the person's previous and current level of engagement in activities from the information provided by the caregiver. The ACS gives the clinician information about the interests, activities, and hobbies of persons to use in planning care. It can be completed in card sort or checklist format.

The Memory and Behavior Problems Checklist (MBPC; Zarit & Anthony, 1986) reports the problems identified by the caregiver in managing the person with cognitive impairment. The instrument has 2 sections: one documenting the presence of the behavior and the second documenting the caregiver's tolerance for the behavior, if it is observed. In addition to recording the presence of disturbing behaviors, such as wandering, rudeness, losing things, and not recognizing others, it also reports the help needed to perform basic and instrumental tasks of daily living. The instrument can be completed in interview or checklist format by the caregiver and provides information that can help the clinician help the caregiver.

The Zarit Burden Interview (Zarit & Anthony, 1986) reports the burden experienced by the caregiver in managing the person with cognitive impairment. It includes questions that address both demand and emotion-focused stress. Demand stress involves issues such as time for self, dependency, access to resources, and social life. Emotion-focused stress addresses issues such as guilt, anger, fear, and embarrassment. The instrument is completed in interview or checklist format by the caregiver.

## A Framework for Intervention

Baum (1993) found that individuals with DAT who remained engaged in activities displayed less difficulty with dressing, feeding, bathing, and grooming and had fewer occurrences of disruptive behaviors. Some have suggested that caregivers should be given formal or informal support with tasks such as bathing and dressing (Miller, McFall, & Montgomery, 1991; Vitaliano, Russo, Breen, Vitello, & Prinz, 1986). Help with the self-care tasks alone would not alleviate the caregiver's stress, as the stress is related to the disturbing behaviors, not the frequency with which help is required in self-care. Some disturbing behaviors may surface during dressing and bathing tasks, particularly if the tasks are presented at a level beyond the impaired person's capability. Figure 31-2 describes relationships that can guide OT intervention.

For individuals to remain engaged in activities as the disease progresses, it is necessary for the caregiver to

compensate for the planning and organizational deficit and memory loss. The caregiver must be taught how to provide the organizational strategies and memory supports that the person with the impairment can no longer provide for him- or herself. Productive behaviors in the form of instrumental, leisure, and social tasks become the mechanism to minimize the disturbing behaviors. To minimize disturbing behaviors, activities important and meaningful to the person must be organized into routines that are consistent from day to day.

Family members derive satisfaction from providing care when the caregiving activities are predictable and controllable (Kinney & Stephens, 1989). Using this explanation, the caregiver would not be stressed by the actual tasks of caring, but by the unpredictability of the occurrence of disturbing behaviors.

The following is a description of the changes that occur in the individual's performance as the disease progresses. The following is also a summary of the performance reported by the caregiver on the FBP (Baum et al., 1993) and staged using the Clinical Dementia Rating (Berg, 1988).

During the earliest stage of the disease, the individuals usually are appropriate in activities and can do what they are asked to do if the instructions are simple. They usually perform activities without frustration and in a reasonable time frame. They may need encouragement to begin a task. It is impossible for persons to learn a new complex activity, but they can perform complex tasks that are overlearned without assistance. The caregivers begin to face problems at this level. One problem concerns the person's ability to drive. Additional problems involve the ability to manage money and maintain relationships.

In the mild stage of the disease, individuals remain appropriate in activities and independent in grooming and hygiene. They can independently do a simple task; however, they often need encouragement to begin the activity and will do better if the tools and supplies they need are placed at the point of use. They need assistance in doing more complex tasks (those with multiple steps).

The next stage of the disease (moderate) is very problematic for the caregiver, as the impaired person can no longer perform any activity without either verbal or physical assistance, meaning that the person cannot be left alone. Impaired persons can still identify familiar persons, and their behaviors are usually appropriate.

In the severe stage, persons cannot do anything for themselves. Often individuals are in nursing homes, but for many reasons (costs ranging from $24,000 to $40,000 per year being just one), a substantial number remain at home. Individuals in this stage can still carry out a response to a one-step command. However, the request must take into consideration their physical capabilities. Specific verbal guidance must be provided to elicit every movement. If you were feeding a person with DAT, you would have to say, "Here, hold this bread. Put it to your mouth. Open your mouth. Take a bite. Chew." The important thing to remember is even though the person appears quite disabled, he or she still has a social need to be part of his or her family social unit and enjoys being a part of interactions (Baum et al., 1993).

Cognitively impaired persons experience anxiety and display disrupting behaviors that may be related to their diminished ability to process information to perform instrumental, self-care, and social activities. Disruptive behaviors include aggressiveness, outbursts, combativeness, wandering, disturbed sleep, incontinence, agitation, insecurity, decreased responsiveness, decreased cheerfulness, irritability, selfishness, crudeness, sexually inappropriate behavior, suspiciousness, the hiding of objects, and repetitious actions (Buckwalter, 1990; Rabins, Mace, & Lucas, 1982; Sinha et al., 1992; Swearer, Drachman, O'Donnell, & Mitchell, 1988). Such behaviors may be indications that the person with cognitive loss is bored or not able to do what he or she wants or needs to do. It can be posited that if the caregiver can set up and support the environment to keep the impaired person engaged in a routine of activities, the effort could potentially minimize the disruptive behaviors of his or her loved one and reduce his or her stress.

OTs and OTAs play a critical role in helping families acquire the knowledge and skills to support their loved one's behavior as they strive to maintain dignity and engage them in activities. There is consensus that activity is important to maintain cognitive and physical health (Almli, 1993; Christiansen, 1991; Fidler & Fidler, 1963; Kielhofner, 1992; Lawton, 1990).

## Occupational Therapy Principles Guiding Treatment

OT offers guiding principles that are basic to developing and implementing a client-centered program for people with cognitive loss.

- An individual's performance results from the relationship between that individual and the specific environment in which the activity occurs (Bronfenbrenner, 1979; Christiansen, 1991).
- Engagement in activity makes it possible for individuals to influence their own physical and cognitive well-being (Csikszentmihalyi, 1988; Fidler & Fidler, 1963).
- There is a dynamic interaction among the biological, social, and environmental factors that underlies the individual's capacity for performance in instrumental, leisure, and social activities (Almli, 1993; Kielhofner, 1992; Lawton, 1990).
- Individuals whose activity is within their capabilities do not demonstrate anxiety or boredom related to the task (Csikszentmihalyi, 1988).

### Problems Experienced by Individuals With Cognitive Deficits

Most individuals with cognitive impairment have predictable behaviors associated with their deficits. The following are common; however, nothing should substitute for assessments that focus on the client's and the caregiver's needs as a treatment plan is developed:

- Difficulty with awareness—They have difficulty making insightful statements, and it is particularly difficult to modify behavior.
- Poor impulse control—They have difficulty thinking before acting.
- Poor short-term memory, although long-term memory is well-preserved.
- Perseveration—They often display inappropriate and repetitious behaviors.
- Difficulty initiating and organizing tasks.
- Difficulty recognizing objects, people, and sounds.
- They present safety problems for family and themselves.
- Changes in their sensory systems limit vision, they do not smell as well, and they do not have the same level of taste, making food not as appetizing.

## TREATMENT STRATEGIES

The social science and occupational science literature provides guidance to practitioners with general strategies to teach the family members of the person with the cognitive loss. The strategies in the Evidence-Based Treatment Strategies chart have been determined to be effective.

### General Strategies to Support Occupation

The following specific strategies can be used by the OTA to help the family member acquire the understanding and skills to help his or her loved one maintain independence.

- Build a consistent schedule; build routines around activities he or she has previously enjoyed.
- Do not expect new learning; perform activities that have been previously overlearned.
- Speak with the person about issues that he or she will hold in long-term memory, as he or she will not be able to store more recent events (e.g., Did you have a nice visit with your daughter yesterday? What did you have for breakfast?).
- Play music from the person's era, not current music.
- Use strong lighting.
- Create contrast on surfaces.
- Avoid distractions, and work in a quiet environment.
- Alter recipes to give them more spice or herb flavor.
- Engage the family in care so they can learn cueing skills and see their loved one perform successfully.
- Find activities that couples can do together.
- Do not expect caregivers to do things for which they need skills.
- Talk openly about the issues of driving and refer the family member to resources.

### Environmental Strategies

- Organize daily activities (occupations) into a consistent pattern.
- Build a message center in the home. Post a weekly schedule and specific daily schedule at the center.
- Provide choices in menu items, activities, and clothing.
- Construct memory books, and ask for the help of the children and grandchildren.
- Pets are great companions and offer a temporal aspect to the day.
- Keep patterns of church attendance or visiting with friends.
- Go to the same restaurant to maintain familiarity with surroundings and menu.
- Continue walking or exercise programs.
- Build a work station. Create a stable environment with tools and items needed to do a task.
- Lay out clothes or items that will be used in a task.
- Continue activities that offer socialization.
- Enroll in a support group (for both the client and caregiver).
- Attend a work-oriented day program.
- Teach the family to engage the person in activities even if he or she is not capable of interacting.
- Help the family choose activities to do together so that socialization is maintained.

Some individuals in the early stage of the disease are able to use self-instruction strategies. These are suggested by Sholberg and Mateer (1989).

- Verbalize out loud each move and the reason for the move before and during execution of the task.
- Whisper rather than verbalize out loud.
- Talk to yourself during the task.
- Switch tasks and repeat the preceding steps.

*Note: Generalizations occur only after direct extended training using real-life situations. With an individual with DAT, only activities that have been previously performed can be used, as the potential for new learning is very limited.*

### Self-Instruction Interventions

- Make lists (gauge improvement on the completeness of the list).
- Proceed with verbalization sequence (above).
- Time management training (Sholberg & Mateer, 1989).
- Time estimation—Estimate time it will take as part of planning.
- Creating time schedules, generate a plan for the activities to be accomplished.
- Execute a plan within scheduled time constraints.
- Calendar, day planner.
- Schedule, have a schedule center in home.
- Sticky notes.

Most persons with DAT require compensatory interventions. Usually, the compensatory strategy is provided by the caregiver, aides, and attendants who often fulfill that role and require training. Interventions that are compensatory include the following:

- Person directed by another person (Luria, 1963).
- Organize the setting.
- Build a daily schedule to foster daily routines.
- Help families learn why their loved ones have difficulty initiating and organizing tasks and activities, and teach them how to cue and organize environments for successful interactions.

Individuals with DAT have lives to live (some live 15 years from the time of diagnosis), as do those who are providing care. The OTA is a key professional to help families learn how to manage their loved one, and how to manage without disrupting the lives of the family.

The ideas presented in this chapter seem intuitive and simple. They are not. Families who are experiencing the behavioral changes of their loved one have a hard time recognizing the behaviors as a neurological problem. Deficits such as agnosia, apraxia, and memory are complex neurological problems, and families have no context to understand them. They know their loved ones are acting differently and making demands on them. The OTA can have a major role in helping them understand that their loved one's behavior is not willful but a plea for help to make sense out of experiences that are too complex or too fast for them to process.

The following case is presented to highlight how effective strategies can help family members manage their loved one with mild stage DAT. A person in the mild stage of the disease was chosen because OT intervention can make a difference in helping the family manage these individuals at home.

## Case Study

### Mr. and Mrs. Johnson

For several years, Mr. Johnson, age 63, had been having difficulties that his family found out of character. He misplaced things, would miss appointments with his plumbing clients, became lost when driving and got frustrated, and frequently lost his keys. He had always been responsible for keeping his company books. Mrs. Johnson took him to the geriatric clinic after the bank talked to her son-in-law about problems with the business account.

On medical examination, there appeared to be no other medical explanation for the symptoms. There was no evidence of hypothyroidism, vitamin $B_{12}$ deficiency, or other potentially reversible causes of dementia, such as severe hypertension, stroke, kidney, or heart disease. Additionally, there was no evidence of drug abuse or psychiatric illness. The physician gave the Johnsons the diagnosis of probable Alzheimer's disease and referred them to the social worker and OT. Additionally, she gave them a packet of information about services available through the Alzheimer's Association.

### Social History

The Johnsons have a strong marriage. Each had their own interests and together they shared their family, church, bowling, and camping interests. They raised 3 children, 2 of whom lived within 6 blocks of their parents. Mr. Johnson finished high school and completed an apprenticeship as a plumber. He worked for a company for 35 years before it closed. For the past 10 years, he managed a small plumbing company with his son-in-law. His wife is a secretary in the chemistry department at a small private college. She is 61 years old and in relatively good health. Since she began a low fat, sugar-free diet and a daily walking program, she had brought her blood sugar under control and lost 25 lb.

### Occupational Therapy Assessment Results

Mr. Johnson displayed no evidence of apraxia, and previous neuropsychological testing had not revealed aphasia nor agnosia. He did have some facial masking that made it difficult for family to read his emotional status. The physician team had identified his level of impairment as CDR (Clinical Dementia Rating) 1 (mild Alzheimer's disease). Characteristics of mild DAT include moderate memory loss, especially for recent events; deficits that interfere

with everyday activities; and moderate difficulty with time relationships. These characteristics were descriptive of Mr. Johnson.

From the KTA, Mr. Johnson's executive skills were impaired. He required verbal cues to initiate, organize, perform all steps, and sequence the kitchen task. He also needed verbal assistance in managing the stove and pouring the hot liquid. He did recognize that the task was finished. He was capable of performing all aspects of the task but needed the presence of a person to verbally cue him throughout the task.

From the FBP, Mrs. Johnson reported that her husband was able to concentrate for long periods of time as evidenced by his daily activity of continuing with plumbing tasks around the house. (She had encouraged him to continue with his plumbing at home after he no longer went to work.) He usually finished tasks that he started (when he had done them in the past), performed his work neatly, and had no trouble using tools or manipulating small items like buttons on clothing. He did need help with his razor, so Mrs. Johnson got him an electric razor, which he could manage. His activities were usually appropriate to the time of day, however, lately he had been waking at night and going to the kitchen to get something to eat. He continued to make decisions concerning what to wear and what to eat, but Mrs. Johnson found that he was better at this when he was given choices. He continued to bathe and groom with only a little encouragement. He really enjoyed getting out to church activities and being with the children and grandchildren. However, Mrs. Johnson reported that he did not want to stay at events as long as she did. He continued to recognize family and most friends, however, friends helped by saying their name when they greeted him. He rarely initiated conversation but conversed when others started the conversation. Family and friends prompted him when he got lost in a story. Rarely did he know what day it was and he could no longer make independent decisions or problem solve.

From the ACS, Mr. Johnson gave up the tasks of managing personal finances, investments, and general car maintenance. He continued to do home repairs and frequently drove on familiar routes in the neighborhood. He managed the telephone, as his wife had programmed and labeled the frequently called numbers. He read the newspaper and watched sports on TV.

He had given up his church committee activities; however, he still enjoyed going to church. He and Mrs. Johnson went bowling each week in a couples' league and went dancing with friends at least twice a month. They did less family visiting and went out to eat less frequently than 1 year ago. He had given up fishing and hunting, but still did woodworking, camping, and gardening, although less frequently than before because he needed to find time when his son or son-in-law could help him. He had always taken a Sunday afternoon ride in the country.

He watched birds in the backyard but could no longer name them all, and he tended his flowers, but not carefully. He needed help to get started and move from task to task. He had given up reading the Bible and reading in general.

Mrs. Johnson still worked full time and worried how she would finish the year so she could collect her early retirement from Social Security. She had help from the daughter and son and their families, but all of them worked so she had limited assistance during the day. Mr. Johnson had worked alongside his son-in-law until 6 weeks ago. Mrs. Johnson reported that the future was frightening to her.

From the Zarit Behavior Problem Checklist, Mrs. Johnson reported that Mr. Johnson occasionally had gotten lost, and she thought it was time to take away the car. She reported that he asks repetitive questions and that it was beginning to get on her nerves. She also indicated that he was misplacing things. She reported that he did not destroy things or do things that could be dangerous to himself or others. However, she said he was frustrated frequently, as evidenced by his yelling at her and the dog; and recently she had found him wandering about the neighborhood. She did not recall that he had reported hearing voices or having hallucinations. If she laid out his clothing, he could dress himself. She indicated that he did not have difficulty with self-care tasks; however, she did have to help him with money. She had programmed the telephone so he could get in touch with her during the day. She admitted that he called her frequently and her office seemed to understand, but she felt that it would be a problem soon. She reported being very committed to providing care for him. She reported that they have had a good marriage and that she continued to feel very close to him.

## Intervention

Strategies suggested by the OT based upon information obtained from the assessment interview and preferences stated by the Johnsons included:

### General Strategies

- Mrs. Johnson was helped to build a consistent schedule. She filled out daily schedules for several weeks until she realized that a consistent schedule had been constructed. She noticed an improvement in Mr. Johnson's behavior when he functioned in a routine.
- Mrs. Johnson was taught to deliver cognitive support. Mr. Johnson mostly required verbal cues and functioned fairly independently when the environment was organized to cue him. It was important to help Mrs. Johnson understand that Mr. Johnson needed help in getting started (initiation) with an activity and also required assistance in getting the task organized. She learned that his difficulty with initiation was not due to stubbornness, but due to the related neurological deficit.

- The family was introduced to cueing strategies, and they chose activities that each of them would be able to do with their father/grandfather, including taking walks, growing flowers, playing with the dog, watching birds, managing house plants, and bowling. Mrs. Johnson integrated these activities into the weekly schedule.
- The family was taught about the related neurological deficits. Because Mr. Johnson displayed some facial masking, it was important for the family to learn to look beyond his facial expression when he was expressing feelings and emotions.

## Strategies to Support Behavior in the Absence of Ability to Solve Problems

- The family built a message center in the home so that Mr. Johnson would have a place to go to find out where Mrs. Johnson was, even if she was in the yard. The weekly schedule and specific daily schedule were posted at the center. The children learned to use the center when they were in the home.
- Mrs. Johnson found that when she gave Mr. Johnson choices in menu items that he eats better. He loves French fries and rather than let him choose them daily, she includes them as a menu choice twice a week. He had never been one to help with dinner preparation, but Mrs. Johnson found that he preferred to be with her and that he would do simple tasks like tearing lettuce or stirring a pot of soup or stew. He can do most any task when she chooses to guide him verbally through the task.

## Strategies to Support Socialization

- A memory book was constructed with the help of the children and grandchildren. This book was to be used to engage Mr. Johnson in conversation and help him remember familiar people and important past events. A special section on birds was included so that he could keep up with his bird watching.
- Bowling and dancing have been an important part of their routine, so Mrs. Johnson is trying to keep them going. His attention span is decreased but he enjoys the socialization that they offer.
- Mr. Johnson is very fond of his dog. The dog actually cues him to let him out and feed him. They are great companions. The dog is always by his side when he is working in the garage. The problem is the dog is old, so the therapist suggested that a younger dog might be a good investment to maintain the companionship in the future.
- Mr. Johnson no longer can manage Sunday School, but he does sit patiently through church. Mrs. Johnson noted that he does better when they go consistently.
- Mrs. Johnson wanted Mr. Johnson to have a process to express his frustrations and concerns, so she enrolled him in the group for persons with mild DAT sponsored by the local Alzheimer's Association. He goes to the group weekly. While he is there, Mrs. Johnson can run errands or meet with the other spouses.
- The Johnsons had always enjoyed going out to dinner. They always go to the same restaurant so that Mr. Johnson can manage the menu and visit with the staff and friends that frequent the restaurant.

## Strategies to Support the Performance of Tasks

- Mr. Johnson began a work-oriented day program where he could use his handyman skills to make toys for underprivileged children.
- A plumbing work station was built in the garage where Mr. Johnson could safely work with his tools and keep busy while at home. His time in this task gave Mrs. Johnson time to do her activities at home.
- He continues to dress himself when she places the clothes in the same order each day.
- Mr. Johnson's driving skills were evaluated by an OT in an on-the-road assessment. It was determined that it was no longer safe for him to drive. Mrs. Johnson takes him to day care on her way to work and picks him up after work. Because Mr. Johnson always liked to see the hills in the country, either his son or son-in-law takes him for a weekly drive to keep him in touch with nature.
- Mrs. Johnson continued with her walking program but included Mr. Johnson. In good weather they used the college track; in inclement weather they walked in the mall.
- The entire family came to understand how important a stable environment was to support Mr. Johnson's function. The grandchildren have learned why his paper should be in the same place, why his tools should not be moved. The family marked their father's bathroom door with a picture of him shaving. A card labeling the TV stations with news (Channel) 4, sports (Channel) 2, etc., was pasted on the back of the remote control so that he could watch his shows. The power button was painted white. The remote is always in a basket on the table by his chair.

When Mr. Johnson stays involved in activities that are important to him, he does not exhibit as many disturbing behaviors as when he is bored or anxious. He particularly enjoys working in his garage workshop. Mr. Johnson's memory has not improved, but the modifications that the family has made is providing an environment that maximizes his function and keeps him active and engaged. Mrs. Johnson reports that she is able to continue working, which is an important goal for both of their long-term security.

## Evidence-Based Treatment Strategies

| *Treatment Strategies* | *Authors* |
|---|---|
| Strengthen remaining capacity of person with impairment | Averbuch & Katz, 1992; Baum & Edwards, 1993; Buettner & Fitzsimmons, 2009; Doody et al., 2001 |
| Keep him or her active and involved | Alessi et al., 2005; Burns & Buell, 1990; Corcoran, 1994; Dougherty & Radomski, 1993; Graff et al., 2007; Ledger & Baker, 2007; Nawate, Kaneko, Hanaoka, & Okamura, 2008; Oakley, 1993; Rolland et al., 2007; Zarit & Anthony, 1986 |
| Practical advice to caregiver | Baum & Edwards, 1993; Cohen, Kennedy, & Eisforder, 1984; Corcoran, 1994; Dooley & Hinojosa, 2004; Dougherty & Radomski, 1993; Eustice, Roe, & Paterson, 2000; Haley, Levine, Brown, Berry, & Hughes, 1987; Josphsson, Backman, Nygard, & Borell, 2000; Oakley, 1993; Ostaszkiewicz, Johnston, & Roe, 2004b; Quayhagen & Quayhagen, 1988; Vitaliano et al., 1986; Zarit, Reever, & Bach-Peterson, 1980 |
| Organization of a schedule | Baum, 1993; Cohen et al., 1984; Corcoran, 1994; Dougherty & Radomski, 1993; McCurry, Gibbons, Logsdon, Vitiello, & Teri, 2003; Oakley, 1993; Ostaszkiewicz et al., 2004a |
| Organization of the environment | Baillon et al., 2004, 2005; Baker et al., 2001; Chard, Liu, & Mulholland, 2009; Dickinson, McLain-Kark, & Marshall-Baker, 1995; Dooley & Hinojosa, 2004; Dougherty & Radomski, 1993; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Heyn, 2003; Kincaid & Peacock, 2003; Oakley, 1993; Toglia, 1992; van Weert, van Dulmen, Spreeuwenberg, Ribbe, & Bensing, 2005; Zarit & Anthony, 1986 |
| Exercise | Quayhagen & Quayhagen, 1988 |
| Maintenance of interpersonal relationships | Cohen et al, 1984; Corcoran, 1994; MacDonald, 1978; Motenko, 1989 |
| Family included in care plan | Clipp & George, 1990; Cohen et al., 1984; Corcoran, 1994; Dougherty & Radomski, 1993; Quayhagen & Quayhagen, 1988 |
| Training in communication skills | Bourgeois, 1993; Dooley & Hinojosa, 2004; Quayhagen & Quayhagen, 1988; Rabins et al., 1982 |

## *Discussion*

Mrs. Johnson was a caregiver with a mission: to maintain a purposeful relationship with her husband, to be a successful caregiver, and to remain at work. She was meeting and continues to meet those goals. Of course there were difficult days, but she had a sense of humor, a very supportive family, and a friendship network at home and at work to help her. She was particularly happy when the Family Leave Bill passed, knowing that she had the resources to manage problems as they arrive and can take some time off if it is necessary.

An adaptive approach was the treatment of choice, not only because it makes good clinical sense, but it was what the family wanted and needed. They were willing to take on their role of caring, they just needed the skills to be successful.

# CLINICAL PROBLEM SOLVING

Mr. and Mrs. Johnson had excellent diagnosis and treatment options as they addressed the problems of Alzheimer's disease. Consider the following case typical of uncertainty in the early stages of proper diagnosis:

Frances is a 72-year-old woman who lived with her family in a major East Coast city. She was admitted to a subacute rehabilitation facility following an acute care hospitalization of 10 days after a fall in the bathtub. Although being treated initially as a person with a head injury, information about her preaccident functioning hinted at other problems. The family was guarded about sharing information and there seemed to be conflicts within the family about "protecting family assets." The client was cooperative but clearly confused. As time went on, information came forward that Frances had been taking a shower, fully clothed including sneakers, when she fell and experienced the head injury. The social worker was concerned about the safety of the home and for Frances' well-being, and asked the treatment team to assess and treat the client keeping in mind that litigation or protective services may become involved.

The OT then completed the Bay Area Functional Performance Evaluation (BaFPE) along with other formal assessments to get a better handle for the client's behavioral functioning. Serious cognitive deficits were documented. The client was first handed a packet of money ($5.00) and asked to complete a budget sheet using a grocery list. Second, the client was asked to draw a house floor plan (5- x 7-inch rectangle) using a list of required rooms. Lastly, the client was asked to draw a person "doing something." Copies of Frances' work are in the Real Records section.

Considering the evidence from the BaFPE, what discharge plans seem appropriate? How can the family become involved in the treatment process? What signs of cognitive disabilities are present in the 3 subtasks of the BaFPE?

## Learning Activities

1. Design a family education tool that addresses how to deal with the frustration that comes with the patient "slowing down."
2. Investigate Internet sites that provide services or supports for people with Alzheimer's disease. Evaluate the trustworthiness of each site.
3. Design a leisure check sheet for a person with Alzheimer's disease. Keep in mind the motor and cognitive issues that can interfere with movement.

## Editor's Note

This chapter was updated by the editor. Dr. Baum was president of the American Occupational Therapy Association at the time of this writing.

## References


Alessi, C. A., Martin, J. L., Webber, A. P., Kim, E. C., Harker, J. O., & Josephson, K. R. (2005). Randomized, controlled trial of a non-pharmacological intervention to improve abnormal sleep/wake patterns in nursing home residents. *Journal of the American Geriatrics Society, 53*, 803-810.

Allender, J., & Kaszniak, A. W. (1989). Processing of emotional cues in patients with dementia of the Alzheimer's type. *International Journal of Neurosciences, 146*(3-4), 147-155.

Almli, C. R. (1993). Abstract: Motor system, development, and neuroplasticity: Implications of theory and practice in OT. AOTF Research Colloquium, Seattle, WA, June 1993.

Alzheimer's Association. (2004). *Fact sheets*. Retrieved from www.alz.org/Resources

American Association of Retired Persons. (2002). *America in 2011: A new vision*. Long Beach, CA: Author.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Averbuch, S., & Katz, N. (1992). Cognitive rehabilitation: A retraining approach for brain-injured adults. In N. Katz (Ed.), *Cognitive rehabilitation: Models for intervention in occupational therapy* (pp. 219-239). Boston, MA: Andover Medical Publishers.

Baillon, S., van Diepen, E., Prettyman, R., Redman, J., Rooke, N., & Campbell, R. (2004). A comparison of the effects of Snoezelen and reminiscence therapy on the agitated behaviour of patients with dementia. *International Journal of Geriatric Psychiatry, 19*, 1047-1052.

Baillon, S., van Diepen, E., Prettyman, R., Rooke, N., Redman, J., & Campbell, R. (2005). Variability in response of older people with dementia to both Snoezelen and reminiscence. *British Journal of Occupational Therapy, 68*, 367-374.

Baker, R., Bell, S., Baker, E., Gibson, S., Holloway, J., Pearce, R., . . . Wareing, L. A. (2001). A randomized controlled trail of the effects of multi-sensory stimulation (MSS) for people with dementia. *British Journal of Clinical Psycholgy, 40*, 81-96.

Baum, C. M. (1993). The effects of occupation on behaviors of persons with senile dementia of the Alzheimer's type and their caregivers. Dissertation. George Warren Brown School of Social Work, Washington University, St. Louis, MO.

Baum, C. M., & Edwards, D. F. (1993). Cognitive performance in senile dementia of the Alzheimer's type: The Kitchen Task Assessment. *American Journal of Occupational Therapy, 47*(5), 431-436.

Baum, C. M., & Edwards, D. (2000). Documenting productive behaviors: Using the Functional Behavior Profile to plan discharge following stroke. *Journal of Gerontological Nursing, 26*, 54.

Baum, C. M., & Edwards, D. F. (2001). *The Washington University Activity Card Sort*. St. Louis, MO: Penultimate Publications.

Baum, C. M., Edwards, D. F., Leavitt, C., Grant, B., & Deuel, R. M. (1988). Performance components in senile dementia of the Alzheimer's type. *Occupational Therapy Journal of Research, 8*, 356-364.

Baum, C. M., Edwards, D. F., & Morrow-Howell, N. (1993). Identification and measurement of productive behaviors in senile dementia of the Alzheimer type. *The Gerontologist, 33*(3), 403-408.

Berg, L. (1988). Clinical dementia rating (CDR). *Psychopharmacology Bulletin, 24*(4), 637-638.

Bourgeois, M. S. (1993). Using memory aids to stimulate conversation and reinforce accurate memories. In *Gerontology Special Interest Section Newsletter* (pp. 1-3). Rockville, MD: American Occupational Therapy Association.

Bronfenbrenner, U. (1979). Purpose and perspective. In U. Bronfenbrenner (Ed.), *The ecology of human development* (pp. 1-15). Cambridge, MA: Harvard University Press.