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Dementia

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The purpose of this chapter is to provide clinicians with the information they need to offer a continuum of AAC services and care for people with dementia. Dementia has many etiologies; the characteristics of the most common ones will be reviewed across types and stages. From there, clinicians will be provided with information about functional assessment tools and intervention strategies for people with dementia and their caregivers. The chapter will also provide information about how AAC can be used to support individuals with dementia as they transition through different service delivery settings (e.g., home to assisted living to nursing home) as well as information about funding issues and available resources. Speech-language pathologists (SLPs) and other clinicians may thus find themselves expanding their ideas about AAC to include a variety of external aids that support memory and facilitate engagement. The interventions that we describe are intended to maximize communicative and memory functioning in ways that will help people with dementia to maintain or increase their activities, participation and engagement, and quality of life across the disease progression. These interventions may also improve the quality of life and decrease the stress of family and professional caregivers of individuals with dementia.

WHAT DO I NEED TO KNOW ABOUT DEMENTIA TO PROVIDE AAC SERVICES?

Definition of Dementia and Types

Dementia is symptomatic of a variety of degenerative neurological diseases. Saying that someone has dementia is like saying that someone has a fever. Instead, the medical team needs to seek a diagnosis for the cause of the symptoms to provide proper medical treatment as appropriate. In addition, the psychiatric symptoms of dementia need to be evaluated according to the symptom profile specified in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association, 2000) to provide appropriate treatment for different dementia subtypes.

According to the DSM-IV-TR, the diagnostic criteria for dementia include memory impairment and related changes in another cognitive domain (language,

abstract thinking, judgment, executive functions) that are sufficiently severe to cause impairment in social and occupational functioning and that reflect a decline from a previously higher level of functioning (American Psychiatric Association, 2000). Cognitive and behavioral symptoms are chronic and progressive, may be correlated with specific neuropathology of an organic basis, and are differentiated from disturbances of consciousness (e.g., delirium, temporary fluctuations in consciousness or awareness) or psychiatric etiologies (e.g., depression, anxiety disorders) for which there are pharmacological treatments (Ballard, 2000). Several conditions may induce dementia symptoms that are treatable and often reversible; however, they must be diagnosed and treated before symptoms become too severe to be reversed (Green, 2005).

Comprehensive medical, neurological, and neuropsychological examinations contribute to an accurate differential diagnosis of dementia. In addition, recent advances in the use and interpretation of data from brain imaging, neurochemistry, and pathology have resulted in the classification of specific dementia subtypes (Sjögren, Wallin, & Blennow, 2003). Some of the more common subtypes include Alzheimer's disease (AD), vascular dementia (VaD; and subtypes Binswanger's disease and multi-infarct dementia), frontotemporal dementias (FTD; and subtypes Pick's disease, primary progressive aphasia, and semantic dementia), and dementia with Lewy bodies. (See Chapter 7 for detailed information on primary progressive aphasia.) In addition, dementia symptoms are commonly present in Parkinson's disease (PD) and related syndromes (e.g., progressive supranuclear palsy, corticobasal degeneration), Huntington's disease, and human immunodeficiency virus (HIV). Finally, Creutzfeldt-Jakob disease (CJD), a rare spongiform encephalopathic disorder of prion proteins, is characterized by rapid deterioration of cognitive skills. CJD has an average duration of 8 months because there are no known effective treatments (Brandel, Delasnerie-Lauprêtre, Laplanche, Hauw, & Alperovitch, 2000).

Reversible Conditions that can Cause Dementia Symptoms (Green, 2005)

- Metabolic conditions (e.g., thyroid and liver disease, diabetes)
- Neoplasms
- Toxins (e.g., alcohol, heavy metals)
- Infections (e.g., meningitis, neurosyphilis, human immunodeficiency virus)
- Autoimmune disorders (e.g., multiple sclerosis, lupus)
- Nutritional disorders (e.g., deficiencies in thiamine, folate, or vitamin B)
- Pharmaceutical drug effects
- Normal-pressure hydrocephalus

Stages of Cognitive Decline and Associated Cognitive-Communicative Problems

The progressive decline in specific cognitive and behavioral symptoms is predictable and distinguishes the different dementia subtypes. See Table 8.1 for a summary of cognitive and behavioral symptoms in AD and other subtypes of dementia.

Alzheimer's Disease

In AD, the earliest and primary presenting symptom is memory impairment, especially in working memory, formerly known as short-term memory (see Table 8.2 for a summary of the types of memory). Working memory, the central executive, is the cognitive process that is most vulnerable to deficits (Paulesu, Frith, & Frackowiak, 1993). This interferes with encoding processes, resulting in less information being

Table 8.2. Types of Memory Processes

I. Sensory Memory (SM)	Involves attention, alertness, arousal processes; transient, initial-stage processing of visual, auditory, tactile, taste, olfactory stimuli; unconscious awareness
II. Working Memory (WM)	Involves encoding and brief storage for all sensory stimuli (formerly known as short-term memory); temporary storage of limited capacity
III. Long-Term Memory (LTM)	Involves retrieval processes and permanent storage of unlimited capacity
Declarative (Explicit)	Person's knowledge base, involves conscious awareness
Semantic	Knowledge of the world, facts, and ideas
Episodic	Knowledge of personal experiences (autobiographical)
Nondeclarative (Implicit)	Person's knowledge of skills and action patterns, involves unconscious awareness
Procedural	Sequenced motor and cognitive skills that become habitual and automatic with practice

Sources: Baddeley, 1999; Sohlberg & Mateer, 2001.

sent to long-term memory. As the disease progresses, damage to retrieval processes can result in decreased recall from long-term memory, particularly semantic and episodic memory stores, although procedural memory is relatively well preserved until the later stages of the disease (Greene, Patterson, Xuereb, & Hodges, 1996). Other cognitive domains, such as visuospatial abilities and the executive functions of initiating, inhibiting, planning, problem solving, organizing, and self-monitoring, decline slowly and progressively over time as memory deteriorates.

In early AD, language difficulties, such as word-finding deficits and comprehension deficits for abstract language and complex conversation, actually reflect early memory, attention, and concentration deficits. Over time, word finding and naming worsen to such an extent that verbal content is characterized as "empty," and indefinite pronouns, and ambiguous or tangential speech increase. Eventually, spoken output devolves from empty speech to echolalic, perseverative, and paraphasic speech, then into incoherent vocalization, and finally to mutism. Reading, writing, and pragmatic skills begin to decline in the middle stages of AD; conversational turn taking and topic maintenance become significantly impaired. By the end stage, communication is severely impaired, and most people become nonverbal and dependent on partners for communicative interaction. Additionally, other behaviors (e.g., personality and mood changes, agitation and repetitiveness, hallucinations and delusions, and eating, sleeping, and sexual disorders) present in subtle forms initially and intensify over time.

Other Degenerative Diseases Associated with Dementia

Table 8.1 outlines the differences in symptom presentation over time for the most prevalent dementia subtypes. VaD is characterized by an abrupt onset of cognitive changes due to focal cerebrovascular infarcts or a stepwise progression of symptoms due to multiple ischemic, small-vessel disease lesions (Richter, 2004). The particular cognitive symptoms depend on where the infarcts occur. Often, VaD leads to focal language deficits and prominent neuropsychiatric symptoms such as depression, anxiety, and apathy (Aharon-Peretz, Kliot, & Tomer, 2000). Unlike AD or VaD, frontotemporal dementia (FTD) is characterized by changes in behaviors and language skills that precede memory loss. In particular, mood and personality changes and ex-

pressive language difficulties (e.g., reduced output, perseverative, stereotypical, and echolalic responses) are evident early in the course of the disease. Similarly, primary progressive aphasia (PPA) is characterized by a slow deterioration of language abilities with marked paraphasic, apraxic, and agrammatic errors but without the personality and behavioral changes of FTD. (See Chapter 7 for detailed information on PPA.)

Dementia with Lewy bodies (DLB) has a distinctive pattern of early attentional, visuospatial, and executive function deficits but intact memory function (Barber, Newby, & McKeith, 2004). Visual and auditory hallucinations, depression, delusions, mood changes, and sleep disorders are particularly salient diagnostic indicators of DLB (Ballard et al., 1999). The pattern of dementia symptoms in PD is similar to that of DLB. People with PD demonstrate fluctuating and markedly slow cognition, executive function impairments that are greater than those in AD, but fewer language and memory deficits than occur in AD (Litvan et al., 1991). The severe neuropsychiatric symptoms of depression, hallucinations, and delusions that accompany PD have been attributed to dopaminergic medications that also can cause psychosis and nightmares (Lieberman, 1998). A variety of additional, PD-like syndromes are also associated with dementia. They can be distinguished on the basis of some specific diagnostic features. For example, the primary diagnostic feature of progressive supranuclear palsy that differentiates it from PD is paralysis of vertical gaze (Litvan et al., 1996). Corticobasal degeneration can be distinguished from PD by the presence of dystonia, focal reflex myoclonus, and one cortical sign (e.g., limb apraxia, sensory loss, alien limb phenomenon; Litvan et al., 1997). Huntington's disease is characterized by early involuntary movement abnormalities (e.g., chorea, dystonia, athetosis, bradykinesia, myoclonus) and intact language and cognition until the later stages (Cummings, 1995). The hallmark cognitive symptoms of HIV-associated dementia are impaired attention and concentration; slowing of mental and motor speed; loss of initiative; and slow, labored, and dysarthric speech (Price, 2003). CJD is distinguished by a rapidly progressive decline in cognitive abilities (within 6 months); early psychiatric symptoms (e.g., depression, delusions, agitation); and ataxia, myoclonus, and involuntary movements (Zeidler et al., 1997).

Preserved Cognitive-Communicative Abilities

Along with the predictable patterns of cognitive decline across dementia etiologies, our understanding of patterns of preserved cognitive and communicative abilities across etiologies has also increased in recent years. The original World Health Organization's (WHO, 1980) classification of impairment, disability, and handicap has evolved to focus more on function. Likewise, researchers and clinicians have an increasing commitment to identifying the strengths and remaining abilities of people with dementia in order to design appropriate and functional treatment goals. An inventory of relatively preserved abilities across etiologies is described next.

Alzheimer's Disease

In early AD, language functioning is relatively intact. Individuals with AD have fluent expression and no phonological or syntactic difficulties; communication deficits are subtle at this point. The many early, preserved abilities include intact phonology,

syntax, pragmatics, oral reading, writing, and comprehension of concrete language and written text. Other skills, such as reading comprehension, attention and concentration, and comprehension of abstract language might fluctuate from apparent normalcy to deficiency within a short period, limiting opportunities to capitalize on moments of lucidity. Other memory domains are relatively intact (implicit, long-term, and sensory) compared to the decline in working memory. Awareness of deficits and insight into the effects of their memory deficits on others are strengths that can be mobilized in the development of plausible support strategies and treatment targets in the early stages of AD.

In the middle stages of AD, phonology, syntax, oral reading, and reading comprehension for familiar text as well as implicit and sensory memory remain relative strengths. Even as the person declines into the later stages of dementia, the basic human need for personal closeness and communicative interaction is reflected in appropriate affective responses (smiling and pleasant vocalizations) and increased cooperation in daily activities in response to personally relevant sensory stimuli (visual, tactile, auditory cues). At this point, these affective behaviors might be the only consistent responses to familiar sensory stimuli.

Other Degenerative Diseases

In VaD, the stepwise progression of symptom exacerbation is reflected in relatively long periods of symptom stability before an abrupt change due to infarction. These periods of stability can be viewed as windows of therapeutic opportunity. If treatment protocols are implemented in a timely fashion after infarction, treatment effects should maintain until the next infarction. The treatment protocol then can be modified to counteract additional deficits.

In FTD, memory and language functions are relatively preserved initially, in contrast to obvious personality, mood, and behavioral changes. However, in frontotemporal lobar degeneration (Pick's disease) and PPA, language deterioration is the primary disturbance, and strengths lie in the areas of intact visuospatial and memory skills, personality, and behavioral functioning. In semantic dementia (SD), anomia is apparent, but language is relatively intact until later in the disease progression. In contrast, relatively preserved memory functioning in the face of prominent psychiatric and motor deficits characterizes the early presentation of DLB, PD, progressive supranuclear palsy, corticobasal degeneration, Huntington's disease, HIV-D, and CJD. Despite some minor differences, the language and cognitive abilities demonstrated by people with these forms of dementia typically maintain until later in disease progression.

Even in dementia subtypes in which cognitive-communicative abilities are not affected until later in the disease progression, SLPs should assist the patient, caregiver, and medical team in planning for the eventual cognitive and language declines. In addition, SLPs should capitalize on preserved abilities across dementia subtypes and stages of severity to provide effective intervention programs. The aim of these programs should be to maximize communicative functioning to maintain (or increase) activities, participation, and quality of life for people with dementia across the disease progression. Overcoming the barriers of depression, apathy, and loss of initiative by capitalizing on cognitive and language strengths will be the challenge to meet for positive outcomes.

Effects of Dementia on Communication Opportunities with Caregivers and Peers

Caregivers, peers, and people with dementia often report a decline in satisfying communication interactions as the disease progresses. This can lead to social isolation and reduced quality of life. Therefore, caregivers and peers (i.e., communication partners) need to be educated periodically in strategies that will allow them to continue to provide satisfying communication opportunities. Because behavioral, cognitive, and language changes in dementia interact across the disease progression, communication partners should be provided with information regarding the causes of communication breakdowns and specific strategies to compensate for those deficits. For example, a caregiver might not recognize that there is a language deficit when a person with early-stage dementia speaks in complete, grammatically and phonologically correct sentences, even if the content of the sentence is meaningless. Similarly, when a person makes word selection or paraphasic errors, the caregiver might not understand that word retrieval is affected by deficits in long-term memory processes. In addition, if memory problems lead a person to feel incompetent, the person might be uncooperative and argue with the caregiver. The caregiver, in turn, might feel attacked undeservedly and might retreat from the interaction or argue back in self-defense. This can result in a negative feedback cycle in which both partners experience dissatisfaction with communication, resulting in fewer communication opportunities. This negative cycle could be prevented through education about the disease, its progression, and its impact on the range of cognitive, language, and behavioral skills of the patient. Therefore, caregivers are important partners in the intervention process. They can provide information about the person with dementia while they learn about the specific features of the patient's dementia subtype and strategies to compensate for deficits and to support remaining abilities. In many cases, caregivers will need specific skills-based training to learn positive interaction styles, behaviors, and appropriate cueing strategies and to inhibit negative, nonproductive behavior patterns.

In the early stage of AD, caregivers need to learn how to support conversation without challenging the person to remember specific words. Caregivers also need to know how to redirect the topic of conversation when working memory losses interfere with attempts to answer the question or concern, and they need to be able to provide a compensatory strategy for the information that needs to be remembered. The overall tenor of intervention at this stage is to help the person maintain conversation in a way that does not draw attention to the memory difficulties or word retrieval problems but focuses on the message. The focus of educational efforts at this stage is to maintain the dignity and self-respect of the person who is experiencing memory loss but who is aware of his or her difficulties.

In the middle stages of AD, when patients lose awareness of their cognitive and communication problems and become more egocentric and less aware of the impact of their behavior on others, caregivers need to learn how to facilitate communicative interactions that maintain social closeness by rehearsing familiar personal history information. It might be difficult to shift the caregiver's expectations of an equitable and balanced relationship with the patient to one that is more one-sided and intended primarily to meet the needs of the patient. This shift in interpersonal focus intensifies as the patient progresses in the disease to the point of requiring nursing care, which is entirely patient-focused. At the end stages of the disease, caregivers

might need to learn how to communicate for the patient and how to use language, tone of voice, familiar objects, and touch to provide comfort and familiarity.

Case Report 1

Mr. Smith, who attended an adult day care facility and was diagnosed with early-stage dementia, enjoyed talking with members of a local service organization. When he first met them, he used his memory wallet, which consisted of thirty pages of biographical information made by his daughter, to tell about his life. At a subsequent visit, when Mr. Smith came to the page that stated, "I worked for the J & L Railroad for thirty years before retiring," he paused before reading the statement, turned over the page, and said, "I bet you didn't know that I started out in the mailroom, then was promoted to clerk, and after a few years worked in maintenance." He had written the words *mailroom*, *clerk*, and *maintenance* on the back of the page.

Nine months later, when Mr. Smith was asked to tell the visitors about his life using the memory wallet, he started reading at the first page, continuing until he reached the last page, and then he started over from the beginning and read until the visitor suggested that they get a snack. A year later, Mr. Smith smiled when asked to talk about his life, held the memory wallet, but did not start reading. When the visitor read the first page aloud, Mr. Smith smiled and patted the picture. As the visitor continued reading each page and commenting about the pictures, Mr. Smith continued smiling and patting the pictures and on occasion would repeat a word that the visitor had said.

This example illustrates the changing nature of the communicative interaction as the disease progresses. In the early stage, Mr. Smith was aware that the visitor had heard that he had worked for the railroad, and he planned to elaborate on that idea by making notes for himself about his different jobs during his career. Mr. Smith, at this stage, was capable of an equitable conversation; his pragmatic awareness was intact, and his language and memory skills allowed him to plan for a more satisfying second conversation. As the disease progressed, Mr. Smith lost that pragmatic awareness, and the conversational interaction became one-sided. When he finished reading his memory wallet and started over, this reflected his desire to maintain social closeness with the visitor; the only way he could remember how to do this was by rereading his memory wallet. By the time the disease had progressed to an advanced stage, Mr. Smith had lost his verbal abilities but not his desire to communicate, which he did by smiling, patting the wallet, and echoing an occasional word. The visitor, at this point, was entirely responsible for carrying on the conversation by reading and elaborating the wallet's content.

When the patient has a type of dementia that first presents with behavioral aberrations, especially mood and personality changes, caregivers will have additional challenges when identifying opportunities for communicative interaction. It can be very difficult to recognize the role that dementia plays when language is accurate but the content is negative or aggressive; caregivers usually accept the words that are spoken at face value and respond in anger or feel hurt and distressed. When interactions between the patient and caregiver become negative, the caregiver might withdraw and avoid interacting with the person altogether. SLPs need to be alert to these negative interaction patterns and provide appropriate education to the caregiver to mediate the interactions and help the caregiver to find positive alternatives for main-

taining interaction. Redirection and other behavior management strategies are successful for many situations and often require specific caregiver training.

Roles of the SLP in Working with People with Dementia Across Etiologies

SLPs must consider a number of variables in creating a treatment plan for people with degenerative neurological diseases, including the balance of cognitive versus language impairments (as well as speech impairments), other behavioral or neuropsychiatric issues, the course of the illness (i.e., stable, recovering, or degenerative), and the stage of the illness. If the dementia syndrome causes relatively more impairment in cognition (e.g., the memory problems present in AD), the SLP should maximize the preserved language skills when developing interventions to support cognition. Alternatively, if focal language disorders are the presenting symptom of the dementia syndrome, the SLP may address the specific language deficits within the context of relatively preserved cognitive processes. When cognition begins to decline as well, the SLP will need to modify therapeutic goals to maximize function with the presenting strengths and deficits. For example, the SLP might decide to target working memory deficits in a person with early-stage AD by teaching the use of written strategies (e.g., a memo board for home chores and a daily planner for appointments). The SLP could teach the person with early VaD and expressive language deficits to use a communication book. In this case, the client should assist in developing the categories and identifying the vocabulary to include in each category.

Many dementia subtypes present with behavioral symptoms as the primary diagnostic characteristic. When depression, apathy, agitation, lack of inhibition, and other mood and personality changes are the presenting symptoms, SLPs also will need to consult with other professionals on the team for a comprehensive and coordinated therapy plan. In some cases, medications will be warranted. In many cases, targeted behavior management plans that include a range of antecedents and consequences for functional behaviors will need to be developed. The SLP's role might be to help determine the nature of appropriate antecedent stimuli or cues (e.g., spoken versus written cues, size and type of font, syntactic complexity or length of written stimuli, use of photos or picture symbols).

The degenerative nature of these dementia syndromes necessitates periodic reevaluation of the patient's skills and deficits and modification of treatment strategies or treatment targets. For example, when a person with AD has used a memory wallet to maintain satisfying conversational interactions with peers at a residential facility but is no longer using it and is observed to be withdrawn and avoiding others, it might be necessary to reconfigure the memory wallet into a memory book with larger print and pages. Similarly, when a person with PPA who had been reading large-print magazines for pleasure is no longer reading them, it might be necessary to develop alternative materials on familiar topics (e.g., a former minister with PPA initially read a large-print Bible and later enjoyed playing an Old and New Testament categorization game using single large-print names such as Moses and Luke). (See Chapter 7 for more information on PPA.)

General Principles of Intervention for Dementia

The degenerative nature of dementia was the rationale for a rather pessimistic view of the therapeutic potential for people with dementia before the late 1980s. Clinicians

were advised to provide supportive services to the families of people diagnosed with dementia because there were no known effective interventions for reversing the inevitable decline in cognitive and behavioral symptoms. However, a number of factors have combined to create a new attitude toward working with people with dementia. There is an increased focus on maintenance of independence for as long as possible and on enhancing quality of life of people with dementia as well as their caregivers. In 1980, the WHO published a conceptual framework for evaluating the medical, functional, and social outcomes of chronic diseases, first known as the International Classification of Impairments, Disabilities, and Handicaps. This original model, as well as the current International Classification of Functioning, Disability and Health (WHO, 2002), was the impetus for clinicians to address a wider variety of treatment targets beyond those designed to reverse impairments. The passage of the Omnibus Budget and Reconciliation Act (OBRA) of 1987 (American Health Care Association, 1990) then mandated cognitive and communicative evaluations and care plans for people with dementia who have been admitted to residential care facilities. Finally, the publication of many behavioral treatment efficacy studies over the past 2 decades has changed the outlook of clinicians in many disciplines. In particular, research has documented the effectiveness of specific behavioral intervention approaches, such as written reminder cards or memory books, that reduce the activity limitations or participation restrictions resulting from an impairment, promoting participation in daily activities. The many potentially effective behavioral treatment approaches for this population are fueling efforts to provide appropriate services to people with dementia and their caregivers, with the recognition that although these treatments will not reverse the impairments caused by the neurological damage, they often can facilitate the maintenance of a high quality of life. In addition, treatments that target compensatory strategies to circumvent impairments can also allow the person with dementia to participate in his or her social milieu in a meaningful way.

We propose that clinicians consider adopting the following three principles of dementia intervention. The primary goals of intervention should be to maintain independent functioning for as long as possible and to maintain quality of life through supported participation and engagement in desired activities; these goals should be achieved through procedures that are personally relevant to the client and are trained within functional contexts. Each principle will be described and applied to a case illustration.

Maintenance of Independent Functioning as Long as Possible

Intervention should begin in the earliest stages of the degenerative condition. This way, individuals are aware of their own deficits and remaining skills, can communicate desired goals and personal preferences, can identify effective memory strategies that they currently use, and can participate in planning and implementing compensatory strategies for future functional losses. An ideal approach is to enhance areas of strength and to reduce demands on impaired systems. As symptoms of dementia progress, external communication and memory aids should be modified accordingly to promote maximal function. Thus, the person can maintain as high a level of independence as possible for as long as possible across the early and middle stages of the disease.

Case Report 2

An SLP received a referral for Mrs. Jones, a 58-year-old woman whose doctor suspected that she had the early signs of a progressive dementia. Mrs. Jones sought assistance in using memory strategies so that she could continue working as an administrative assistant in the dental office where she had worked for the past 15 years. She was concerned that she would lose her job if anyone found out about her possible dementia. The SLP and Mrs. Jones identified several external memory strategies that would enhance Mrs. Jones's ability to do her job, including the routine use of a daily planner, checklists, and Post-It note reminders. As the disease progressed, they modified these strategies and eventually enlisted the support of her husband and coworkers in continuing to use these strategies and in modifying her responsibilities so that Mrs. Jones could maintain employment.

Maintenance of Quality of Life via Supported Participation and Engagement

Activities that define the individual's lifestyle and personality must be identified in order to match them with compensatory strategies and the potential need for caregiver or partner training. A variety of life activities, ranging from employment to volunteer jobs to leisure activities, can be analyzed for potential compensatory supports that can be implemented by the individual or by trained caregivers or peers. Arkin (1996, 2001) described a supported volunteer program in which college students were paired with adults with dementia and accompanied them to their volunteer activities (e.g., animal shelter, hospital) for enhanced socialization and cognitive support to complete the activities.

Case Report 3

An SLP received a referral for Mr. MacDonald, a 76-year-old man who wanted to continue functioning as a lector in weekly church services but was having difficulty reading from the prayer booklet. The clinician determined the relevant task variables (e.g., length and complexity of text to be read, size and style of type font, task familiarity or predictability) and selected a compensatory strategy that would support the behavior (e.g., shorter reading selections, enlarged print, and scheduled practice). Mr. MacDonald was able to continue in this role until cognitive deficits limited his reading at the paragraph level. To continue to participate actively in the church community, he then served as a greeter and handed out church bulletins before services.

Emphasis on Personal Relevance and Contextual Training

The importance of selecting treatment targets and activities on the basis of the person's lifelong interests and habits is paramount in addressing motivation and treatment adherence issues. As clinicians, we know that the client who is motivated and has participated in the selection of treatment targets and activities will be most likely

to carry out the treatment plan; we usually do not have much optimism for those who must be cajoled and convinced to attempt a specific protocol or strategy. Therefore, it is ideal to plan treatment and compensatory strategy implementation with motivated people who are in the early stages. However, when that window of opportunity has closed, the next best option is to know which interests and activities are held in high regard by the client and then plan modifications and supports that will facilitate the maintenance of those activities. Eisner (2001) has developed an approach for the selection of interest-appropriate materials and activities that is based on the personal strengths and interests of the individual. Camp and colleagues (Camp & Skrajner, 2004; Camp et al., 1997) have also developed successful interventions for people with dementia that maintain previous skills and strengths, are personally relevant, and seem to contribute to a positive self-perception. For example, early-stage dementia patients were trained to be leaders of a small-group activity for people with more advanced dementia. They demonstrated effective leadership skills and increased engagement, satisfaction, and pleasure in comparison to standard activity programming (Camp & Skrajner, 2004).

The principle of providing treatment in the context in which the desired behavior is to be displayed is particularly important with degenerative conditions in which the expectation for generalization to other situations and contexts may be limited. To the extent possible, it is necessary to provide training and practice in the specific environment where the behavior is to occur (e.g., the person's kitchen, living room, or bathroom). If a more traditional training venue is used (e.g., the SLP's office or therapy room), there is more potential for delayed training effects or failure to use the compensatory strategy. In this age of increasing constraints on reimbursement, it is imperative that the most efficient treatment models be implemented.

Case Report 4

An SLP received a referral for Mrs. Riordan, a 68-year-old woman. She was still living at home but was beginning to have difficulty with cooking because she forgot ingredients in familiar recipes and could not remember how to sequence cooking tasks for multiple dishes. During assessment, the clinician determined that visual supports for the sequence of cooking would facilitate maintenance of independent skills. An illustrated picture recipe book and practice opportunities were introduced in Mrs. Riordan's kitchen, where the actual food and supplies served as additional cues for the task. Mrs. Riordan was more likely to be successful in this case than if the training was conducted in an office setting without the typical visual cues of her own kitchen.

WHAT ARE THE ASSESSMENT STRATEGIES FOR PEOPLE WITH DEMENTIA?

During diagnostic evaluations for dementia, a full complement of language and cognitive assessment batteries will be completed. That process is beyond the scope of this chapter. Here, we are concerned with assessment for functional treatment planning. If available, the SLP will review the diagnostic evaluation and identify the general areas of cognitive-linguistic impairments and strengths or preserved skills. This information will guide hypotheses about functional performance related to

communication activities and participation. The SLP will then test these hypotheses, using the more functional tools and measures described below. The purpose of assessment for treatment planning is to identify goals, select compensatory strategies, and ascertain training needs.

Screening of sensory function (e.g., hearing, vision) is an essential part of treatment planning. The recommended functional and compensatory treatment strategies will involve the delivery of cues that are appropriate for the sensory and cognitive abilities of the individual. Therefore, it is important to begin assessing a person with dementia by screening hearing and visual acuity. An efficient hearing screening includes pure-tone audiometric screening, informal word recognition testing, and a hearing aid check. Vision screening consists of checking glasses and asking the individual to read signs in the environment.

Another key component of assessment is the case history interview with the patient and caregivers to gather data regarding specific problem areas, desired treatment goals, and expectations for treatment outcome. This will facilitate the selection of specific assessment and trial therapy tasks. The interview should also gather information about the person's activities and interests and the extent of participation in those activities (both prior and desired future participation). People who live in residential facilities may have more caregivers and different treatment needs than those living at home with family; assessment tools for determining functional treatment strategies for those settings will be discussed below. Other functional assessment tools may include formal and informal tests, behavior logs, observations, and checklists.

Tests

Assessment for treatment planning may involve standardized tests, particularly if these are required as documentation for third-party reimbursement. However, the SLP should be aware that many of these tests do not provide information that is useful in functional treatment planning. Informal tests can be much more useful in determining treatment goals and strategies. See Table 8.3 for examples of assessment tools and the advantages and disadvantages of using each type of measure.

Informal Protocols

Clinicians have developed several protocols to determine the most problematic behaviors and care needs for individuals with dementia, which then are addressed by functional treatment goals. For example, if caregivers state that the most troublesome behaviors are repeated questions, refusals to bathe, and loss of interest in lifelong hobbies, the clinician should develop goals that reduce question asking, increase compliance, and increase engagement in familiar activities. Treatment outcome measures also will need to be specific to those behaviors; it is unreasonable to expect gains on a standardized test when the treatment goal modified a specific functional behavior. Accordingly, the frequency of the target behaviors will need to be assessed before treatment to determine the effects of the treatment. Caregivers and family members can be enlisted to keep track of the daily frequency of problem behaviors, particularly when they have identified these behaviors as desired treatment targets. The behavior diary and log shown in Form 8.1 (available on the accompanying CD-ROM) are simple recording methods that caregivers have used successfully to document problem behaviors.

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Table 8.3. Advantages and Disadvantages of Common Assessment Tools for Treatment Planning

Tests	Advantages	Disadvantages
<p>Standardized global cognitive measures:</p> <p>Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975)</p> <p>Burns Brief Inventory of Communication and Cognition (Burns, 1997)</p> <p>Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005)</p> <p>Global Deterioration Scale (GDS; Reisberg, Ferris, Leon, & Crook, 1982)</p>	Obtain ballpark idea of functioning, severity level	Not specific enough to determine individual's strengths and weaknesses
<p>Standardized test battery for impairments:</p> <p>Arizona Battery for Communication Disorders in Dementia (ABCD; Bayles & Tomoeda, 1993)</p>	Comprehensive measure that documents impairments; may identify relative strength areas	Often too lengthy to give in one sitting; might not help identify potentially successful functional treatment domains; not sensitive to changes due to treatment (e.g., goal attainment)
<p>Standardized test batteries for activities:</p> <p>Functional Linguistic Communication Inventory (FLCI; Bayles & Tomoeda, 1994)</p> <p>Rivermead Behavioural Memory Test (Wilson, Cockburn, & Baddeley, 1985)</p>	More functional tasks, may indicate types of cues/stimuli to use for treatment	Although similar to daily stimuli, tasks might be too decontextualized to give indicator of actual performance; not sensitive to changes due to treatment (e.g., goal attainment)
<p>Functional assessment tools:</p> <p>Bourgeois Oral Reading Measure (Bourgeois, 1992b; see Form 8.4 on the accompanying CD-ROM)</p> <p>Spaced Retrieval Screen (Brush & Camp, 1998; see Form 8.5 on the accompanying CD-ROM)</p>	Determines expectation for effectiveness of cues and learning potential; brief	Stimuli might not be personally relevant
<p>Assessment of problem behaviors:</p> <p>Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD; Reisberg et al., 1987)</p> <p>Cohen Mansfield Agitation Inventory (Cohen-Mansfield & Billig, 1986)</p> <p>The Nursing Home Behavior Problem Scale (Ray, Taylor, Lichtenstein, & Meador, 1992)</p> <p>Caregiver interview and forms (Behavior Diary and Log [Form 8.1]; Bourgeois & Hopper, 2005); see also Forms 8.2, 8.3, and 8.6</p>	Important for identifying treatment goals based on specific behaviors to increase or decrease	Requires input from others (family and professionals)
<p>Observational protocols:</p> <p>Functional Goals Screening Protocol: Community Clients with Dementia (Bourgeois & Rozsa, 2005; see Form 8.2 on the accompanying CD-ROM)</p> <p>Screening Protocol to Monitor Residents with Dementia (Rozsa & Bourgeois, 2005; see Form 8.3 on the accompanying CD-ROM)</p>	Important for identifying treatment goals, cueing strategies, and setting specifics (partners, activities, locations)	Requires observation over time, different locations, and multiple informants

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Table 8.3. (continued)

Tests	Advantages	Disadvantages
Interview protocols:		
Personal Wants, Needs, & Safety Assessment (Bourgeois, 2006a; see Form 8.6 on the accompanying CD-ROM)	Necessary for personalized treatment materials and appropriate goal planning	Requires input from others (family and professionals)
Memory Aid Information: Community Version (Bourgeois, 1992b; see Form 8.7 on the accompanying CD-ROM)		
Memory Aid Information: Nursing Home Version (Bourgeois, 1992b; see Form 8.8 on the accompanying CD-ROM)		

It is important to note that documenting problem behaviors has helped some caregivers modify their own perceptions of the intensity of a particular problem. One caregiver insisted that her husband's worst problem behavior was that he yelled at their grandchildren all the time. At the end of a week of recording the actual episodes of yelling, she reported that this behavior in fact did not occur very often at all, and it happened only in very specific situations that were easily preventable. The clinician then designed treatment plans for other behaviors that did occur more frequently.

It is also useful for caregivers to complete forms that identify their expectations for treatment outcome before treatment planning. Caregivers can complete forms to indicate the client's daily schedule and routine (see the example in Figure 8.1) and desired participation level (see Figure 8.2). These forms can provide additional insights into potential treatment goals and can serve as measures of treatment outcomes.

Observation

Observation can be used for treatment planning as well as for trial therapy. In treatment planning, the SLP should observe the person with dementia in his or her environment to assess the person's responsiveness to a variety of cues. Observation can also determine ways to design functional treatment protocols so that the person can practice the desired behaviors in the actual setting and with the actual materials that he or she will be expected to use on a daily basis. Several forms can assist clinicians in documenting the types of behaviors that would be conducive to functional goal development. These include the *Functional Goals Screening Protocol: Community Clients with Dementia* (Bourgeois & Rozsa, 2005; see Form 8.2 on the accompanying CD-ROM) and the *Screening Protocol to Monitor Residents with Dementia* (Rozsa & Bourgeois, 2005; see Form 8.3 on the accompanying CD-ROM). Both of these forms provide a way to document cognitive and communication behaviors, visual behaviors (attention and receptivity to visual stimuli), auditory behaviors (attention to talking, noise, music), tactile behaviors (attention to physical objects, touch), and environmental variables (interaction, initiation with others, active/passive participation) in home, community, and residential settings.

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
8 a.m.	Breakfast Dressed						
9 a.m.							
10 a.m.	Senior Center		Senior Center				Church
11 a.m.							
Noon	Lunch						
1 p.m.							
2 p.m.							
3 p.m.							
4 p.m.							
5 p.m.	Dinner	Dinner	Dinner	Dinner		Dinner	Dinner
6 p.m.	TV news				Dinner at son's house		
7 p.m.		Choir Practice					
8 p.m.							
9 p.m.							
10 p.m.							
11 p.m.	Bed	Bed	Bed	Bed	Bed	Bed	Bed

Figure 8.1. A client's daily schedule and routine.

Observing trial therapy also can help to determine reasonable expectations for obtaining treatment goals. Third-party payers often require documentation of potential for achieving treatment goals and a statement justifying reasonable expectation for goal attainment. The following two screening protocols have been useful for documenting expectation for improved treatment outcomes. The *Bourgeois Oral Reading Screen* (BORS; Bourgeois, 1992b) determines the potential for written cues to effectively cue appropriate communication and cognitive behaviors (see Form 8.4 on the accompanying CD-ROM). However, performance on this task does not always predict whether a person can use written cues for conversations about personal information. Some people with significant cognitive impairments will not be able to read sentences that are personally irrelevant but will read sentences that are personally relevant. In addition, some patients will not follow the instructions to read the sentences orally but will give some other indication of reading comprehension (e.g., "I hate baseball!" or "I live in Tallahassee! Who wrote this?"). Similarly, the *Spaced Retrieval Screen* (Brush & Camp, 1998) (Form 8.5 on the accompanying CD-ROM) determines learning potential for factual information; if the patient can recall the stated fact after a 1-minute delay within three trials, this person may learn

aturday	Sunday
	Church
inner	Dinner
ed	Bed

Environment/activity	People	Frequency of contact	Problems
Home	me wife, Mary	24-7	Lots of arguments Loss of intimacy
Church	Minister; friends: Bob & Jane Smith, H. Jones; many others	Sunday, Tuesday choir practice	Can't remember names
Senior center	men's group	Wednesday	Names, following conversation
Grocery store	clerk	varies	Giving correct money
Son's home	son, spouse, T. (6 yrs), M. (2 yrs)	Once per week	Yells at kids

Figure 8.2. Desired participation level of client.

other facts and strategies using a repetition-based training paradigm. More on this training approach is described below.

Interviews

Treatment planning also involves development of treatment materials. To ensure that strategies and stimuli are personally relevant, patients and caregivers should be interviewed to obtain personally relevant information. (Forms 8.6–8.8 on the accompanying CD-ROM provide protocols to determine personal wants, needs and safety information, and memory book content.) If the individual with dementia is in long-term care, the SLP should check the medical chart to see whether similar forms have already been completed by the individual, family, social workers, recreation staff, or pastoral staff.

Case Report 5

Mr. LeBlanc, a 77-year-old retired truck driver, was referred to the speech therapy department at a rehabilitation hospital following his discharge from the hospital for hip replacement surgery. His medical records documented a prior diagnosis of dementia and periods of confusion, agitation, and noncompliance with nursing instructions during his hospital stay. During the SLP's first meeting with Mr. LeBlanc, she screened his cognitive function using the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), his hearing and vision function, his functional reading ability with the BORS, and his ability to learn the name of the rehabilitation facility using the *Spaced Retrieval Screen*. He scored within the moderate severity of dementia range on the MMSE, had adequate hearing and vision for one-on-one communicative interactions, was able to read 14-point print, and remembered the name of the facility after a 1-minute delay. A meeting with his wife revealed that Mr. LeBlanc was anxious to return home to feed his dogs. However, she was concerned that he would not remember to call for assistance when getting out of bed and therefore would fall again. The SLP decided to develop short-term goals related to using visual reminders to cue use of the call button, to remind Mr. LeBlanc of his physical status, and to recall the facility and therapy routine. The therapy

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program also focused on training his wife and the staff to place the written cue cards within Mr. LeBlanc's visual range and then to prompt him to refer to them. In addition, the SLP enlisted his wife's assistance to make a memory book that included pictures and text about Mr. LeBlanc's current medical condition and the care of his dogs.

WHAT ARE THE SPECIFIC AAC TREATMENT STRATEGIES FOR DEMENTIA?

When working with people who have dementia, SLPs design and teach strategies for enhancing communication, for supporting memory, and for supporting participation and engagement in daily life activities. Problem behaviors are often a consequence of communication or memory deficits, boredom, or social isolation; the communication-based interventions discussed below should also reduce problem behaviors. Examples of specific interventions and modifications across early, middle, and late stages of the dementias will be discussed.

Enhancing Communication

The communication of thoughts, ideas, and feelings is at risk when a degenerative neurological condition interferes with the expression and comprehension of verbal information. Faced with a range of communicative challenges associated with dementia syndromes, clinicians have developed functional tools to support communication at various levels of severity. Memory wallets were first developed by Bourgeois (1990) to enhance the conversational interactions of people with early- to middle-stage dementia and their family members. In her research protocol, memory wallets contained 3- by 5-inch pages on which one simple, declarative statement of fact was written and one illustrative picture or photograph was pasted. These collections significantly increased the number of factual statements made between people with dementia and a communication partner during 5-minute conversations. Additionally, the use of memory wallets during conversations contributed to decreases in the frequency of ambiguous, erroneous, perseverative, and unintelligible utterances. Subsequent replications of the effects of memory wallets on the conversational interactions between people with dementia at various stages of dementia severity and a range of conversational partners (e.g., spouse, friend, volunteer, nursing assistant) demonstrated the utility of this simple, straightforward, memory-enhancing communication tool (Bourgeois, 1992a; Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Bourgeois & Mason, 1996; Hoerster, Hickey, & Bourgeois, 2001). Figure 8.3 illustrates memory wallet and memory book formats across the dementia severity continuum.

The visual and physical characteristics of the communication/memory aid have important effects on communication and conversational participation for people with dementia. For example, when people with dementia had difficulty seeing the print or turning the pages of a memory wallet, simply enlarging the type size and font and constructing a memory book in an 8½- by 11-inch album format allowed individuals to continue to read aloud, elaborate about each picture or topic, and turn the pages with ease (Bourgeois, 1992a). Second, the complexity and vocabulary of the text need to be addressed when the memory aid is first constructed and later when the disease causes sensory and cognitive changes. The text should

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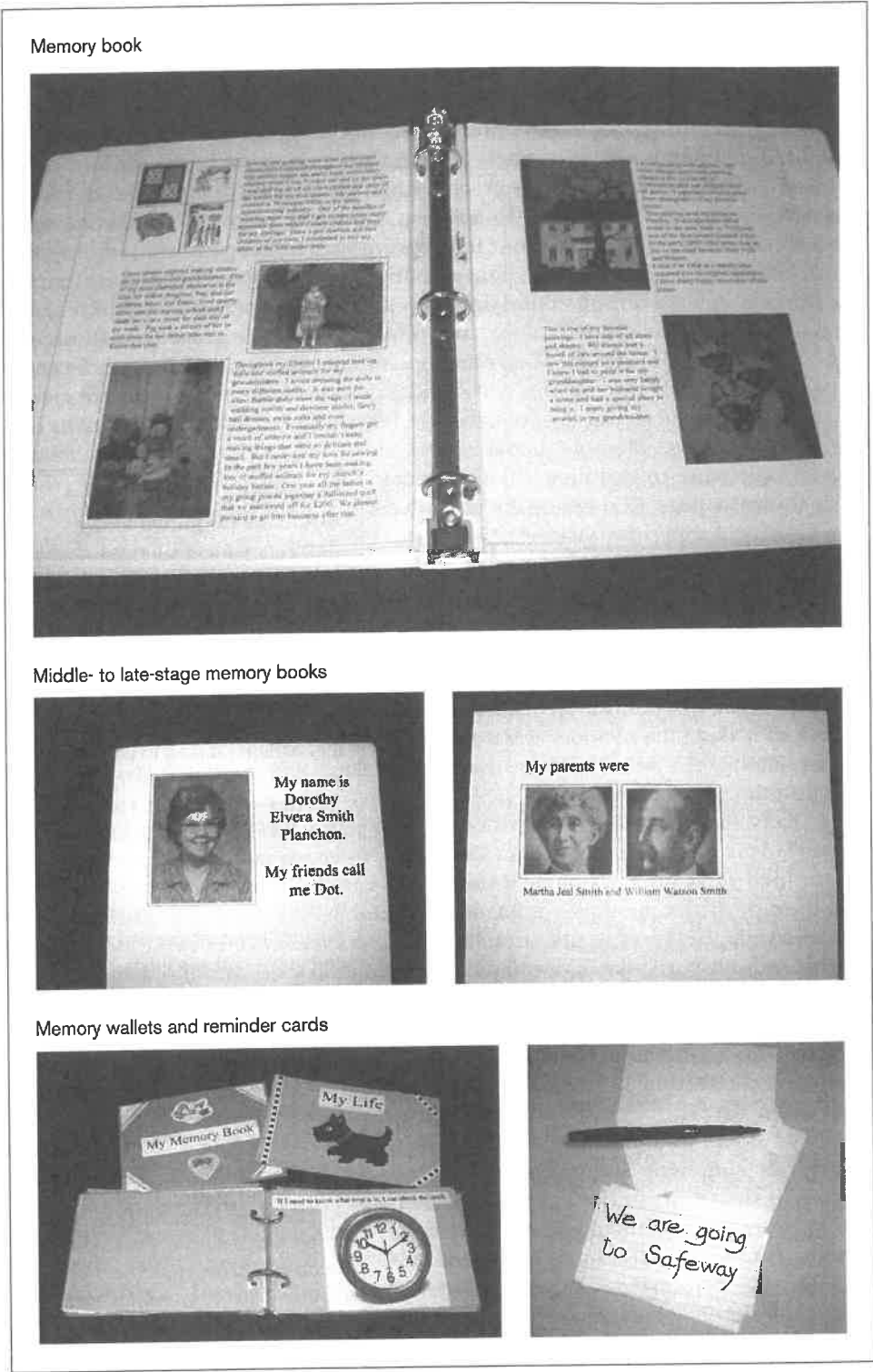


Figure 8.3. Memory wallets and memory books across the dementia continuum.

reflect the individual's style of speaking and vocabulary preferences to make reading aloud and elaboration of the sentences more natural. Third, the portability of the memory wallet or memory book needs to be considered to maximize use in a variety of situations. In nursing homes, memory books often are put into bedside drawers and rarely used. However, Bourgeois and colleagues (2001) made portable, laminated memory books and attached them to a necklace or vest worn by the residents or to the residents' walkers or wheelchairs to ensure their availability across situations in the nursing home. In addition, these memory aids contained some pages that were designed to facilitate interactions with nursing assistants during personal care activities. For example, if the nursing assistant knows that the resident frequently gets agitated during wound dressing changes, the nursing assistant can hand the resident a memory wallet to hold and discuss during the procedure. Bourgeois and colleagues (2001) reported that nursing assistants found portable memory books to be useful in their interactions with residents with dementia. The nursing assistants were observed to use the book to have personally relevant conversations during care activities. Memory books also appeared to increase cooperation when residents were shown a page describing the intended care activity in a positive manner. A variety of wearing devices (e.g., vests, waist packs, or aprons with clear pockets, lanyards, necklaces, belts, wristbands) and wheelchair or walker bags can be used for attaching the aid to the person; patterns for making these devices are available in the work of Bourgeois (2007). The success of making the memory aids wearable is often related to the individual's involvement in selecting the portability choices.

Finally, the need for training to use memory aids to enhance communication should be determined through assessment protocols or trial therapy. If the memory aid has been developed with the appropriate stimulus characteristics for a particular individual in mind, there might not be a need for training. The person might recognize the utility of the aid because the information is familiar, important, and comforting to them. Most individuals, when first introduced to their memory wallet or book, automatically read the text, sometimes comment about what they have read, and then turn to the next page. When the individual has difficulty reading or does not show any interest in what is presented, it is important to determine whether the physical characteristics, vocabulary selection, and complexity of the materials are appropriate. After the size, format, and content of the book have

Modifications to Memory Books as Cognitive and Sensory Needs Change

Visual and physical characteristics

Example 1: A volunteer made a memory wallet for an individual attending adult day services. The volunteer was disappointed that this person refused to participate in conversations using the wallet. The SLP observed that the resident had visual and motor challenges, so she suggested that the volunteer enlarge the wallet to a book-sized aid. The volunteer and the individual proceeded to have enjoyable conversations.

Complexity and vocabulary of text

Example 2: A daughter made a memory book for her mother that included short, three- to four-sentence paragraphs describing each picture. When her mother lost interest in the memory book, the daughter replaced each paragraph with a single, short sentence in a larger type font. Her mother then rediscovered her memory book, spending many hours reading aloud the short captions.

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been customized for the individual, the appropriate oral reading and conversational behaviors will emerge in most cases.

Training may be indicated for some individuals when memory deficits interfere with utilization of the memory aid. For example, when the person forgets that he has a memory aid to support conversation, he might benefit from instruction to learn that fact, or his caregiver could learn to make the memory aid available for conversational situations. The spaced retrieval training protocol has been documented to be a successful strategy for teaching individuals to remember to use memory aids in a variety of situations (Bourgeois et al., 2003). This training protocol uses an instructional strategy called "errorless learning over increasing intervals" to maximize learning potential so that individuals can recall the target behavior. For example, the client with dementia is taught to use a cue card to recall proper transfer procedures. The clinician states, "Before you go from your bed to your wheelchair, you read this card. What do you do before you go from your bed to your wheelchair?" The client is not allowed to make an error, as the clinician intervenes with the correct response if there is not an immediate correct response. After every correct response, the time between recall intervals is gradually extended. See Brush and Camp (1998) for more information on the spaced retrieval technique.

Written strategies such as memory aids are useful for a variety of word-finding problems that are often the first signs of memory loss and can contribute to withdrawal or avoidance of social conversations. An example of a written strategy for word-finding difficulty is to add lists of names and words to the back pages of a planner. These can be words that are very important to the individual (e.g., family and place names, words related to favorite activities) or those that have been forgotten in past conversations. In clinical practice, people have reported that this strategy is successful for maintaining confidence in conversational situations.

In the middle stages of the disease, conversations begin to change in obvious ways. Individuals show less pragmatic awareness of partner needs, which results in impaired turn taking and an egocentric monopoly of the conversation. Without conversational equity, part-

continued

Example 3: A wife selected a variety of photos and captions for her husband's memory wallet. Whenever he turned to the page that stated, "My hobby was woodcarving," he would argue that he never had time for hobbies because of his busy medical career. However, when asked to describe the picture of his woodcarvings without referring to the caption, he remarked, "Those are some of my woodcarvings. Woodcarving was my avocation." When the caption was rephrased using his word, "avocation," instead of his wife's word, "hobbies," he read that memory wallet page without anger and successfully reminisced about his lifelong interest.

Physical characteristics and portability

Example 4: Before taking a resident to the shower, a nursing assistant showed him the page that stated, "Showers help me feel fresh and clean." This enhanced the resident's comprehension of the nursing assistant's verbal instructions and increased his cooperation with going to the shower.

Example 5: A nursing assistant needed to complete difficult and painful care activities with a resident but did not want the resident to become upset. The assistant used the resident's personal memory book to prompt conversation about his personal life and family, thereby distracting him from the unpleasant task in a positive way. Thus, care routines became more pleasant for both.

ners might avoid interactions with the person who has dementia. They might need to be counseled about ways to help maintain conversational behavior at this stage of the disease. If other people with dementia are available (i.e., in an assisted living or residential situation), staff should be advised to prompt residents to share their memory aids with each other to promote conversation. Bourgeois (1993) found that staff could easily arrange "normal-looking" conversational interactions between two residents, thus relieving staff of having to interact with residents when they had other tasks to accomplish. Another advantage of this arrangement was that the conversational partner with dementia did not seem aware when the other person started over from the beginning of the memory book or repeated the same stories.

Case Report 6

Sometimes, it is frustrating to make a memory book and find it everywhere but with the resident. Mrs. Thomas had a memory book to help her to transition into living in a long-term care facility as well as to enhance her conversations with others. The SLP knew that Mrs. Thomas really enjoyed telling stories about her family and life, so the SLP was frustrated that the nursing assistants were not following the care plan, which stated that the memory book should be given to Mrs. Thomas when she got into her wheelchair in the morning. Every time the SLP found the memory book at the nurses' station, she would return it to Mrs. Thomas. One day, several families came in for an activity program—"happy hour"—and the SLP observed Mrs. Thomas interacting with the young grandson of another resident. The boy asked Mrs. Thomas, "Do you have any grandchildren?" She replied, "Just a minute, honey" and went to get her memory book at the nurses' station. She proceeded to have a conversation with the boy. Afterward, Mrs. Thomas returned the memory book to the nurses' station "for safekeeping." Sometimes, we need to follow our client's lead!

In the end stages of dementia, the deterioration of language skills impedes conversations initiated by the resident. Caregivers and family members have to assume responsibility for providing the appropriate stimuli to trigger engagement in the interaction. Conversation cards or memory book pages with extra-large pictures and single words or short phrases, such as "My wedding day" or "My beloved husband, Jeff," can help an individual to gain focus and increase comprehension during an interaction. Interest albums with minimal text can also help to maintain interest in a familiar hobby or pastime. Family members have made baseball albums with team names and pictures, garden albums with flower names and pictures, and other personal interest-specific themes. These albums can be particularly useful for helping family members to feel that they have made a connection with an individual with severe communication deficits. For some people with severe impairments, three-dimensional stimuli related to past work or hobbies, such as dolls, stuffed animals, or memorabilia (e.g., sporting medals, fabric swatches, doilies), will better facilitate interaction. Family members should be counseled to look for nonverbal expressions of pleasure and comprehension such as smiles, pleasant vocalizations, and patting or rubbing the pictures or objects. If the person displays echolalia by repeating what others say, this should be interpreted as an important communicative behavior, one

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that gives the person with severe impairments a very basic way to participate in the conversation.

Case Report 7

Mr. Schulman, the spouse of a woman with Alzheimer's disease who resided in a long-term care facility, observed that other nursing home residents had memory books and decided that his wife should have one, too. The SLP had not seen Mrs. Schulman for speech-language services, because she thought that the woman had advanced to the point of not being able to benefit from skilled services. However, Mr. Schulman persisted in his requests for a memory book, so the SLP instructed a volunteer to make one using large photos from Mrs. Schulman's childhood and young adult years accompanied by simple text in large print. Mr. Schulman reported to the SLP that his wife really liked the book and that his visits were much more satisfying now. The SLP asked, "How do you know she likes it?" He reported, "She smiles and hums when she's looking at it!" The SLP learned that even people with severe cognitive-communicative deficits might benefit from skilled services to design external memory and communication aids.

Supporting Memory

As was stated above, memory is the cognitive skill that declines first in many dementias, foreshadowing further cognitive deterioration. As they age, most people experience the aggravation of forgetting someone's name or a word during conversation. Most people resort to written strategies to support their fickle memories: written notes, a telephone number on a scrap of paper, shopping lists, calendars, and planners. Satisfaction with these strategies leads to more consistent use and more success in the activities for which they are designed. If a client is not using a previously recommended strategy, the SLP needs to work with the client to modify it. Figure 8.4 illustrates memory aids for the early stages of dementia; other useful memory aids include a weekly meal planner and shopping lists (Dohrmann, 1994).

Case Report 8

An SLP received a referral for Mr. Franken, an 82-year-old man who had mild-to-moderate memory deficits. His children were concerned that he spent too much money at the grocery store, buying things that he did not need. When asked about strategy use, Mr. Franken reported, "I don't bother with lists any more because I can't find anything anyway, so I just wander up and down the aisles picking out things I need." Because of his memory and organization problems, the SLP worked with Mr. Franken and his family to design a sheet for grocery lists that was organized by aisle. She recommended that Mr. Franken keep one on the refrigerator to fill in when he realizes items are needed and then take the list to the store to help him remember what to buy and where the items are located. Mr. Franken was pleased that grocery shopping took much less time, and his family was pleased that he was not spending extra money.

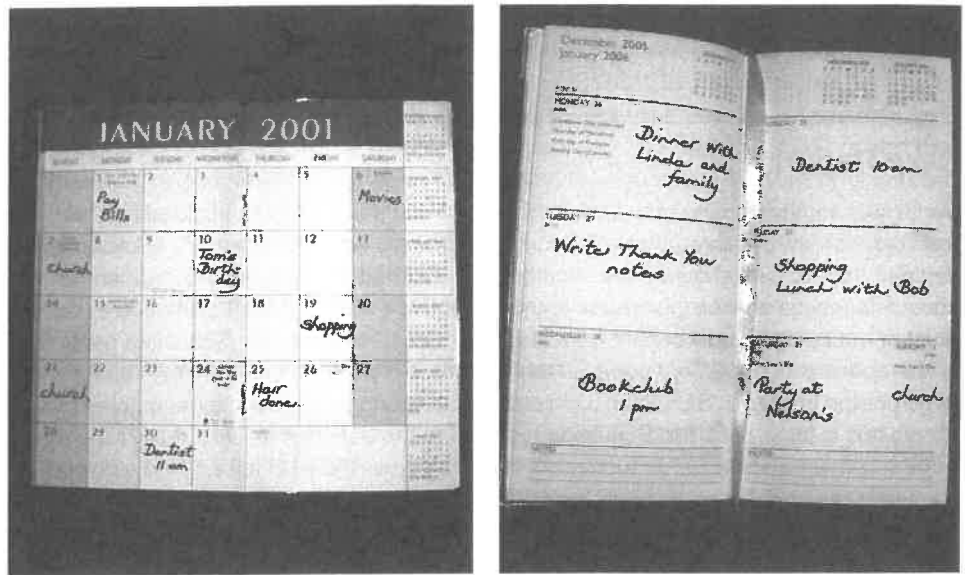


Figure 8.4. Memory aids for early stage dementia.

In the early stages of dementia, common technology can be used as memory supports. For example, a cell phone can be a valuable memory support in a number of ways. The telephone directory can be programmed to dial familiar numbers when the written name appears on the screen, the calendar can be used to keep track of appointments, and the telephone can be programmed to signal when medications need to be taken. There are also many varieties of pill boxes that can be used to support proper medication administration; people with dementia and their caregivers often benefit from an electronic pill box with alarms for medication administration and for recording missed administrations (see Resources at the end of this chapter). In addition, remote keyless automobile access devices that cause the taillights to blink can serve as a car locator in a parking lot. Only a few of the many memory-supporting devices and systems are available to the general public. (See Bourgeois, 2006, for a comprehensive review of external memory aids.)

When memory problems become more persistent and begin to interfere with everyday functioning, memory strategies and memory supports have to become more obvious to the individual if they are to be used consistently. Strategies discussed above that were implemented during an earlier stage of memory loss should continue to be effective with occasional reminders to use them or with modifications. For example, the person who previously used a cell phone could now use a large-button telephone with memory dial capability and a cue card for the steps to dial. The person who consulted the family calendar every morning after breakfast can continue referring to the calendar for information about the date and the day's activities. Figure 8.5 illustrates memory aids for the middle stages of dementia.

After a memory aid has been established, family members can be instructed in some simple prompting and redirection techniques to help establish new routines to support use of memory aids, such as a calendar, a memo board, or reminder



As memory in a number of ways when keep track of medications used to support caregivers (administration of this chapter). Tailor to any memory- Bourgeois,

interfere with the ability to become strategies designed to reduce loss should be modifications. Use a large number of steps to dial. Breakfast can be the day's accent. Instructed in new routines or reminder

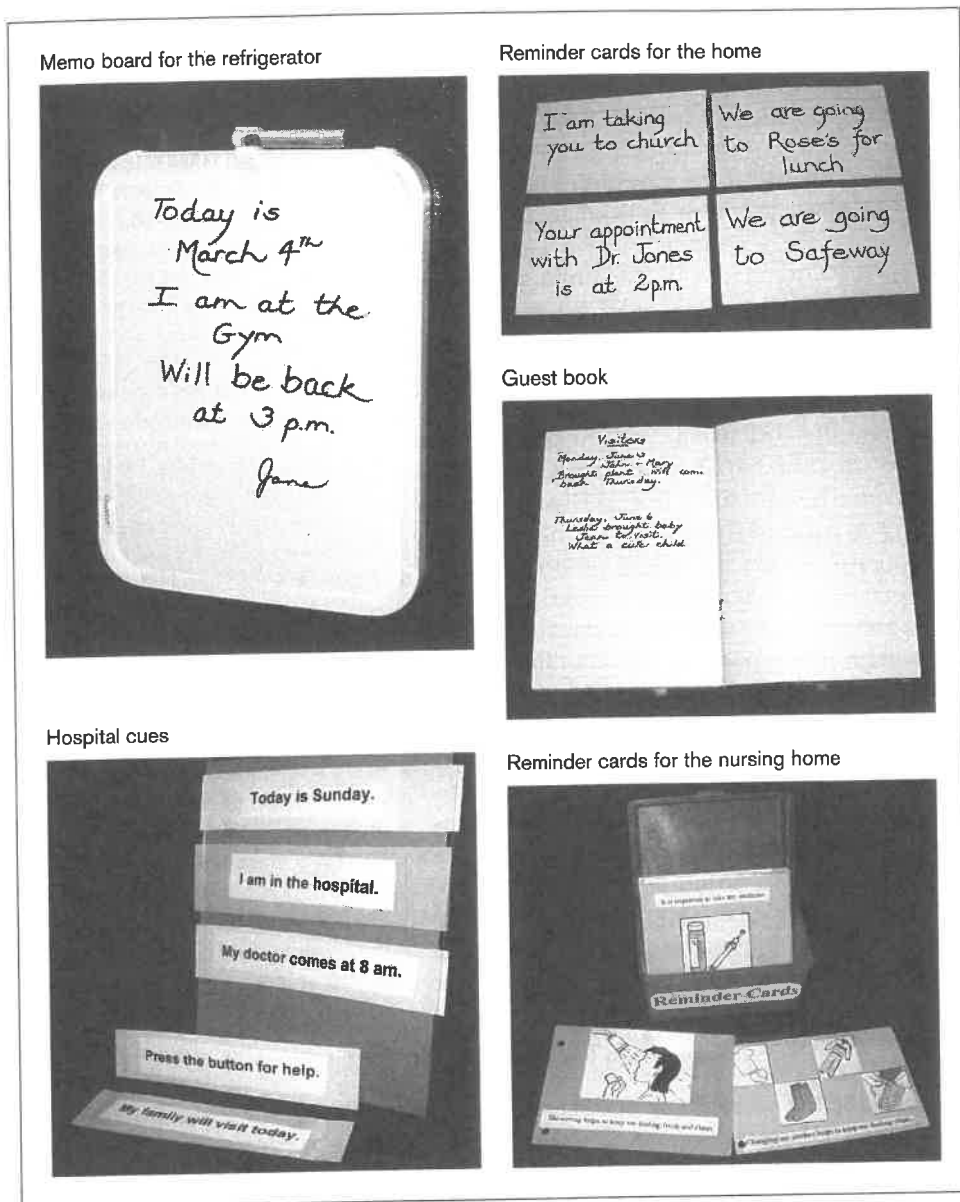


Figure 8.5. Memory aids for various settings.

cards. In the middle stage of dementia, repetitive questions can be stressful to caregivers, who might think that the person is doing this deliberately. The use of written cues for repetitive behaviors has been shown to be effective in reducing the occurrence of these behaviors (Bourgeois et al., 1997, 2001). In the nursing home setting, nursing aides were instructed in the use of reminder cards to help their residents understand and cooperate with daily care activities (Bourgeois et al., 2001). Though skeptical at first, nursing assistants quickly saw the benefits of using a reminder

card that stated, "Eating keeps me strong and healthy" to reduce meal refusals or a memory card that provided personal information as a distraction during unpleasant tasks. Form 8.9 on the accompanying CD-ROM is a useful instructional handout for caregivers on how to use reminder cards with individuals who have moderate-stage dementia.

In the later stages of dementia, memory for personal information can be supported through multiple sensory channels. When auditory information becomes too difficult to process and comprehension is impaired, providing physically and visually salient objects can help to trigger familiar memories. Collections of personal memorabilia (e.g., a cigar box containing an expired fishing license, old identification cards, ticket stubs, and photos) can be comforting in their familiarity and allow the person to physically manipulate the objects and reminisce about past events. Familiar smells and sounds can trigger contentment even when the words to label or express an idea are no longer accessible. Familiar music often invites participation by clapping, tapping, or humming along; when someone with dementia occasionally sings the song's refrain, the power of the appropriate stimulus is evident. Family members and friends should be encouraged to use familiar objects and pictures that could trigger happy memories of long ago.

Cue Cards Used by Family Caregivers

Example 1: When Mrs. Boyle repeatedly asked what was planned for the day, Mr. Boyle gave her an index card on which was written several activities for the day. He instructed her to read her card whenever she asked him what they were going to do, and she stopped asking him the questions because she carried the card with her and consulted it periodically.

Example 2: When Mrs. Porter became agitated and fearful when left alone, she would pace around the house looking for her husband. When he wrote her a note about his plans on a memo board on the refrigerator, she would remember where he was and when he was coming home.

Example 3: Mr. Scott reported using a reminder card when driving with his wife. When she asked repeatedly where they were going, he would make a card that stated, "We are going to church," which she then read frequently during the trip.

Supporting Participation and Engagement

Maintaining the pleasurable and satisfying activities of one's daily life should be the objective of clinicians and family alike; without the pleasures of activities that make us unique individuals, there would be little reason to keep living. Unfortunately, many of those activities are complex and require the same skills that are deteriorating. A classic example of decreased participation is the request by the avid bridge player's friends that her husband plan alternative activities for the usual bridge day so that they can avoid confronting her with the fact that she can no longer play competitive bridge. Another example occurs when the family of a voracious reader notices that she has checked the same book out of the library repeatedly for several months and that she deflects questions about what she is reading with comments such as "I'm so busy lately, I can hardly keep up with my reading." The loyal lay reader who begins to decline invitations to participate in the church service with the excuse "I'm needing to get my glasses checked" provides another example of symptomatic behaviors. This change in participation often occurs too slowly to be noticed by others and is rarely attributed to memory impairment. However,

the avoidance of familiar activities and social withdrawal does, in fact, signal the individual's emerging awareness that cognitive skills are not as sharp as they once were. The astute clinician will obtain a complete list of familiar and pleasurable hobbies and activities, past and current levels of participation in those activities, and a rank ordering of the most important activities to maintain for future enjoyment. With this information, the clinician can focus on designing supportive strategies for the most important activities. Figure 8.6 demonstrates memory and communication aids to enhance engagement and participation.

As was noted earlier, the physical characteristics (e.g., print size) and complexity (e.g., linguistic complexity) of the activity or task need to be assessed. If the size of the print in the reading materials is too small, large-print books and magazines are available for purchase or loan. Reading materials generated on the computer can be designed by using the appropriate font size for comfortable reading. A person who enjoyed reading technical journals in his or her professional area might enjoy a popular press science magazine when the person's cognitive skills begin to decline and interfere with the comprehension of complex ideas. The person who enjoyed the role as a lector in church could maintain this function with larger-print materials to read; with some advance planning, family members can provide assistance in enlarging the week's readings on a copy machine or by retyping them in a larger font. When the rules of a card game become a memory challenge, simpler games can be substituted; the bridge player might continue to enjoy playing cards when the game is Crazy Eights or Old Maid.

Second, the person might benefit from having written instructions or other written prompts to support his or her engagement with familiar activities. Illustrated, step-by-step cookbooks can help to maintain cooking skills and the creation of an edible product. Memory books, reminder cards, and memo boards with written activity suggestions are useful for reminding people of the activities they would enjoy doing. Written instruction cards for operating the television, radio, computer, or other electronic devices reduce the frustrations inherent in those complex machines.

Finally, activities in the individual's specific interest areas will need to be modified so that they attract the person's attention and allow the person to engage in the

Cue cards used by professional caregivers

Example 1: In one nursing home, all residents were given a handout each morning that listed the menu for lunch and dinner on one side and the schedule of activities on the other side. When a resident repeatedly asked, "What are we going to do today?" staff members cued her to look at the printed schedule.

Example 2: A resident who was placed in her wheelchair in front of the nursing station consistently sought attention and interaction from the staff by asking repetitive questions about who would take her to the next activity or meal of the day. The staff became very stressed by this questioning. The SLP put index cards at the nurse's station and instructed the staff to make a cue card with the answer to the question (e.g., "Joe will take me to Bingo") and give the card to the resident, saying, "Read the card." They were further instructed to provide the resident with positive interaction when she was not asking repetitive questions (e.g., "Mrs. Walsh, you look so nice today, that's a beautiful shirt"). The resident reduced her repetitive questions and enjoyed more positive interaction with the staff.

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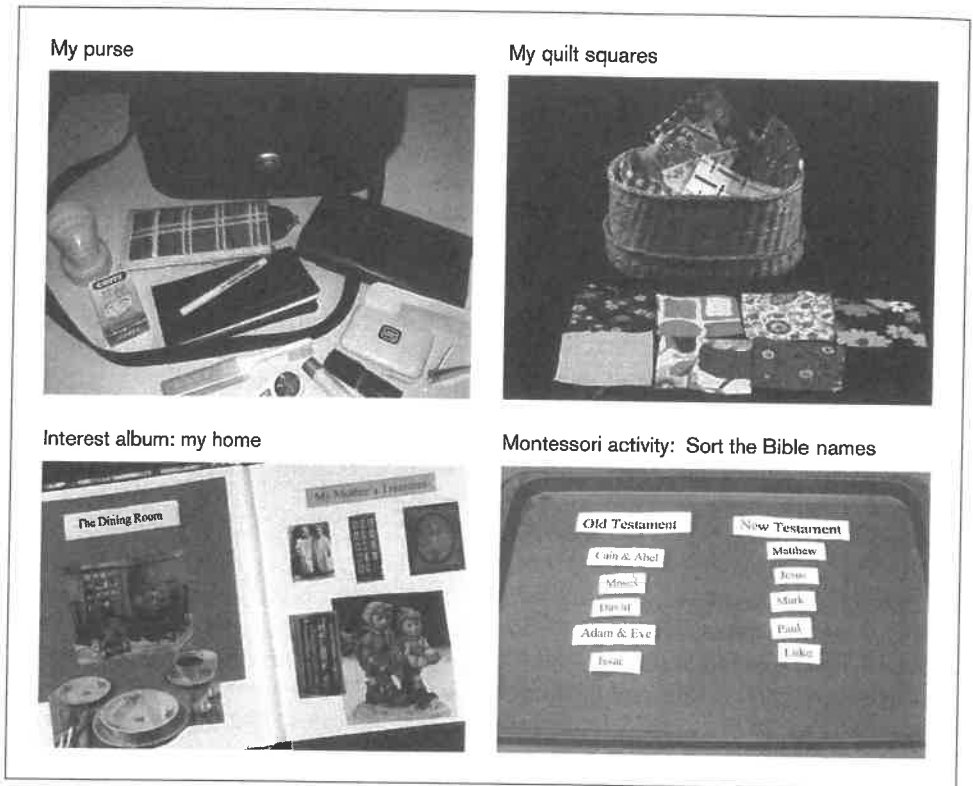


Figure 8.6. Memory aids that enhance engagement and participation.

activity for a significant amount of time. The lifelong activities of an accountant, such as managing and handling money, can be adapted to interesting but easier tasks (e.g., organizing and wrapping coins; Eisner, 2001). Camp's (1999) guidebook of Montessori-based activities for people with dementia includes sorting, organizing, and sequencing tasks that can be modified for the specific interests and hobbies of an individual client. Clinicians often have to help family members identify and simplify favorite activities for continued engagement and enjoyment.

It is important to remember, however, that simply providing visual cues and enhancements might not be sufficient for improving participation and engagement. The person with dementia might need practice using the cuing system to a criterion level that will maximize his or her potential to maintain the behavior after treatment. In some cases, caregivers need to learn how to provide appropriate prompts in order to maintain an effective cuing system. Caregivers also need to be educated to alert the clinician or physician when an improved behavior begins to decline, signaling the need for a modification of the cuing system.

In the end stages of a dementia condition, participation and engagement in activities might be completely under the control of caregivers. They will need to ensure that the person is surrounded by the people and activities that have given him or her pleasure in the past. Memory books, interest albums, and modified activities will need to be provided by the caregivers; they might need to read aloud from the memory book or describe the pictures in the interest album to engage the individ-

ual in a satisfying interaction. They need to feel empowered about their ability to affect the person's emotional state; helping the person to notice signs of comprehension and pleasure (e.g., smiling, pleasant vocalizations) will be important targets of caregiver training. It will be the caregivers' responsibility to provide conditions that are conducive to high-quality engagement. However, changing the expectations of family members requires patience and sensitivity on the part of clinicians. Training or support group sessions that provide education and emotional support to caregivers at the end stages can be particularly valuable for ensuring a good quality of life for both the individuals with dementia and their caregivers.

Case Report 9

Mr. Garcia, who had worked as a mechanic for more than 70 years, entered a long-term care facility. Mr. Garcia was not able to discuss details of his work but frequently got into trouble as he wandered around the facility looking for something to do. He did not engage in conversations with the other residents or staff, even when others initiated. An activities assistant made a memory box constructed from a toolbox, labeled with the name of the auto body shop where Mr. Garcia had worked for all those years. Inside, she put toy cars, pictures of cars and car parts, tools, and other memorabilia that would allow the resident to reminisce about his time as a mechanic. The staff were instructed to place the toolbox near the resident whenever he began wandering and looking for something to do. Mr. Garcia's troublesome behaviors decreased, and the staff were able to enjoy interactions with him related to his favorite topic.

WHAT EFFECT DO SETTING TRANSITIONS HAVE ON AAC INTERVENTIONS?

Home and Community

Most people with dementia will experience the full trajectory of their degenerative condition while living at home and participating in the community (Schulz, 2000). From the prediagnosis phase, when typical age-related memory supports (e.g., planners, calendars, written notes, shopping lists, maps) are adopted, to the early stages when more overt memory supports are implemented, through the end stages, when caregivers assume responsibility for daily activities, the person with dementia and his or her family can transition through the entire range of memory-supporting systems described above. The extent to which these memory supports maintain satisfactory functioning in the home will depend on the caregiver's attitude, skills, and health. The caregiver who is willing and able to seek advice and implement suggestions for addressing problem behaviors will be successful in keeping the patient at home for the duration of the illness. This caregiver will be able to learn strategies for maintaining functional behaviors and to modify techniques as the patient declines. Memory books and interest albums will keep the person conversing about familiar people and activities; memo boards and reminder cards will provide some independence in remembering important facts and reducing repeated questions; and activity modifications will keep the person engaged in familiar life long hobbies.



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Day Care

When the caregiver begins to experience the stress of providing continuous care, adult day care can provide a welcome respite. In this setting, the person with dementia has the opportunity for social interaction and participation in stimulating activities that supplement those that are available in the home. Staff members are trained to recognize the signs of memory impairment and to respond in appropriate ways, and activities are designed to provide opportunities for engagement at the appropriate level of cognitive ability. Some caregivers, however, do not take advantage of day care respite opportunities because of fears that the person will refuse to participate or will be fearful of abandonment. Written memory supports can be very useful in helping the person (and his or her caregiver) transition to this new setting. Reminder cards with statements such as "I am spending the day with friends. My wife will pick me up at 4:30" or a memory wallet with pages that describe the facility and activities (e.g., "I enjoy my time at Joe's Place," "I play pool with Fred and Sam," "The meals are delicious") can help to prepare people with dementia for their day at the center. Staff members can prompt individuals with dementia to read their card or memory wallet when they ask questions about leaving. People who have a memory book should be encouraged to bring them to the center to share with other individuals; activity staff often design group discussions around common topics in memory books, such as "Let's talk about our parents" or "Where did everyone go to school?" Bourgeois and Mason (1996) taught volunteers in an adult day care center to make memory books for people with dementia and to use these for group activities; the success of this program was evident when the other people at the facility, even those without dementia, requested memory books of their own to share with each other. Another useful suggestion for day care staff is to prepare a simple, large-print list of the day's activities at the center that can be copied and sent home with each person. When the caregiver asks the person about the past day, instead of the typical response, "We didn't do anything," the person can read the list of activities and comment about each one. This memory-supporting tool is particularly useful for alleviating the guilt many caregivers feel about having others care for their family member.

Montessori Interventions for Participation/Engagement

Example 1: A former minister enjoyed sorting biblical names into New and Old Testament columns. He also enjoyed sequencing the lines of familiar prayers that were typed in large print, cut into strips, and mixed up.

Example 2: The Civil War buff enjoyed sorting generals' names into columns labeled "The Blues and The Grays" or "Union and Confederate."

Example 3: A former accomplished and prize-winning quilter, who could no longer use a needle and thread to stitch her quilt pieces, was observed happily engaged with a sewing basket of multicolored quilt squares that she patiently arranged in patterns on the tabletop.

Assisted Living

Residents of assisted living facilities are usually transitioning from the totally independent living environment of their own homes to the semi-independent and semi-supervised situation of a private room or apartment in a communal living situation. Some people welcome the comforts, safety, and social benefits of living with other

people and transition easily. Others resist the limitations imposed by a reduced living space, the periodic monitoring of their activities, and the privacy issues that accompany residential living. Personal losses can also create barriers to successful acclimation to a new living arrangement; some residents grieve for lost possessions, their deceased partners, their former home and neighborhood, and their independence. They might withdraw from socialization, avoid communal meals, and decline invitations to participate in activities. If individuals are also suffering from memory loss and cognitive decline, they may experience periods of disorientation and confusion in their new surroundings.

Several memory-supportive tools can ease a difficult transition. A memory album that illustrates the home that has just been left, including pictures of the different rooms with the personal objects, furniture, and memorabilia, can be a comfort. It is helpful to include some written text explaining the circumstances of the move (e.g., "My heart condition worries my family. I will be safer living close to other people" or "I was often lonely at home alone. Here I will make many new friends."). Staff members can suggest that people read their memory book when they get confused or ask to be taken home. Other repetitive requests, such as wanting to drive their car, can be redirected with a memory book page that states, "I enjoyed driving my car around town, but now I don't have to worry about the gas and insurance. Whenever I need to go somewhere, my son drives me in his car."

Assisted living facilities typically support residents in their daily functions with written text in various formats. A quick stroll through an assisted living facility will reveal writing in the form of identification signs on resident rooms and staff offices, newspapers and magazines, menus posted near the dining room, activity schedule boards, and staff name tags. Clinicians working in this environment can encourage their clients to read and respond appropriately to these written cues. When the text is too small or too complex, suggestions for modifying these written supports can be made to the activity staff, who might have the needed supplies for making suggested changes. For example, visually enhancing the day on an activity calendar with a colorful frame can increase the likelihood that residents will be able to find the day's activities. Some clinicians have been successful in convincing the local newspaper to publish a large-print insert of news and announcements once a week for subscribers who used to enjoy reading the paper but now have visual and cognitive limitations (Eaves, July 12, 2003, personal communication); adult literacy resources are also useful (see Resources at the end of this chapter). Printed invitations to attend a specific facility activity can make the reluctant resident feel welcome, and a daily printed menu slipped under the resident's door might entice him or her to try a meal in the dining room. A large-print directory of important telephone numbers by the telephone in the person's room, with notes about when specific family members are at work or home, can help the person to feel that it is possible to contact family when needed. Figure 8.7 illustrates some useful memory aids for assisted living settings.

Long-Term Care

When medical needs necessitate the move to long-term care, this transition can be facilitated with written supports similar to those used in the assisted living facility. Memory books and wallets, reminder cards, and memo boards can all include text explaining the move to the new facility (e.g., "My new home is Magnolia Manor. I

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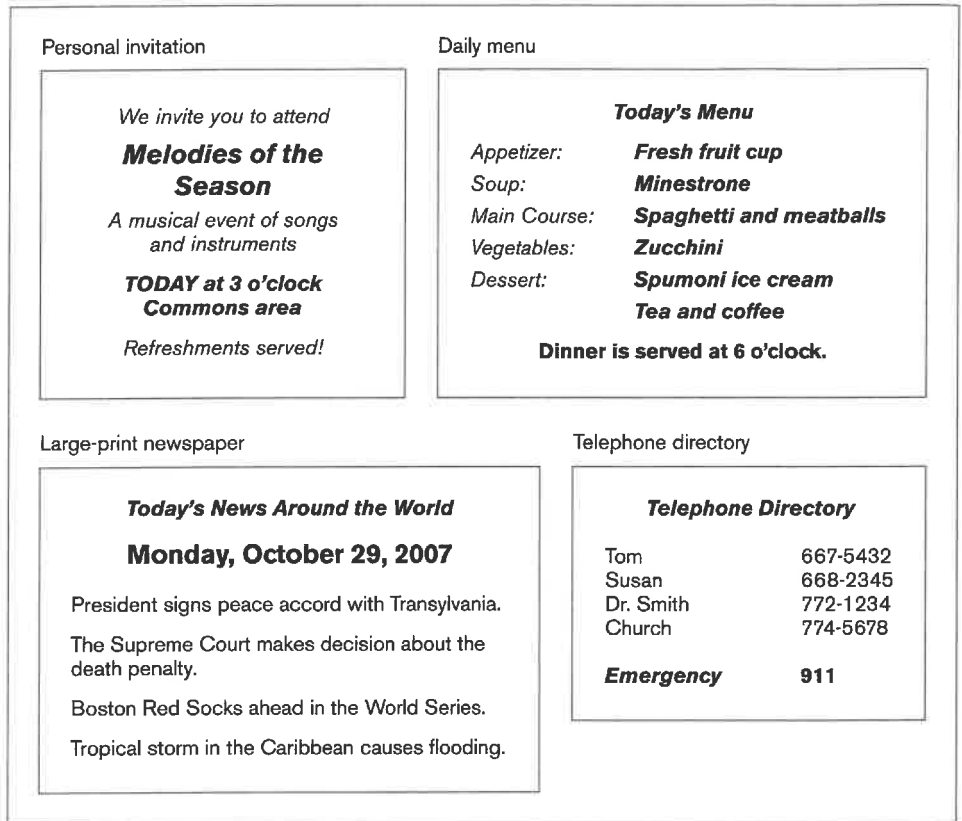


Figure 8.7. Memory aids for assisted living.

am safe here.”). A memory book containing personal biographical information and pictures or an interest album about a favorite hobby can be useful for quiet times when staff members are busy and the person can review the book independently. Repeated requests for the family can be answered truthfully if the resident has a guest book in which family members write notes about their visits and when they will be back (e.g., “I see here that your son writes he will be back to visit on Tuesday—that’s tomorrow.”). Family photos and other personal memorabilia should be labeled in large print; it is the experience of many long-term care staff that when they ask about the people in the photos, the resident either cannot remember the accurate names or makes mistakes in naming them. Staff can use a family video to comfort or redirect a confused or agitated resident; clinicians can suggest to family that they videotape themselves and other family members having a conversation with their relative. For residents who do not have family to make a personal video-

A Family Member's Videotape Script to Ease Transition to a Nursing Home

“Hi, Grandma. I'm Ashley, and I got all As on my report card today, see? [putting the card up to the camera] I like school, and I want to be a teacher some day like you were. [pause] How are you feeling today? [pause] After school, I go to my friend's house, and we play with our dolls [showing dolls to the camera]. This is my favorite doll, Heather. She's wearing a wedding dress. Did you like to play with dolls? [pause] What else did you do for fun? [pause]”

tape, Lund and colleagues (Caserta & Lund, 2002; Lund, Hill, Caserta, & Wright, 1995) produced and tested a series of videotapes designed specifically for people with dementia. These highly interactive videotapes have been documented to engage the person with dementia in a variety of therapeutic activities (e.g., reminiscence, music, exercise) for longer periods of time than other video presentations (e.g., classic movies, television shows).

Case Report 10

Mrs. Friedman, an 82-year-old woman with early-stage dementia, lived in an assisted living facility. After falling and breaking her hip, Mrs. Friedman moved to skilled nursing within the same facility for rehabilitation, with the plan to stay there for long-term care. Because of her dementia, Mrs. Friedman could not remember that she had broken her hip or that she had moved to a different floor in the facility. She also had difficulty recalling her treatment goals and strategies when working with the physical and occupational therapists. Mrs. Friedman had been in rehabilitation for 3 weeks when the SLP started to see her. The occupational therapist had made her a "memory book" that was simply a notepad with a few notes in it, which Mrs. Friedman did not acknowledge. Therefore, the SLP designed a memory book with sections for information about her broken hip and precautions, treatment goals and strategies, and a daily schedule. Because her cognitive deficits were relatively mild, Mrs. Friedman was able to use a fairly complex book with only written information. The SLP used spaced retrieval training to teach Mrs. Friedman to use the book. As her rehab was coming to an end, Mrs. Friedman was concerned about how she would spend her days. She was able to walk with her walker independently, so the SLP used spaced retrieval to train her to walk down the hall, look at the blackboard to see what activities were planned for the day, and write them into her daily schedule. Soon, Mrs. Friedman was carrying the book in her walker basket, attending many activities, and telling everyone in the facility, "See this blue book—that's my brain!"

Acute Care

When the person with dementia enters an acute care setting, it is often because of a medical condition that required anesthesia, is painful, or is treated with strong medications. In all of these cases, the effects of impaired cognition and the consequences of the medical intervention compound the patient's inability to function appropriately or at premorbid levels. Nurses often provide medical instructions verbally (e.g., "The call button is right here. Use it when you feel you need to get up.") with the expectation that the patient understands and will remember later in the day. Unfortunately, most residents with impaired cognition before the medical intervention have even more impaired cognition immediately afterward and are therefore unable to respond appropriately. When the nurses exhaust their patience with repeated instructions, family members are often called on to monitor the patient around the clock.

Some simple written tools can facilitate comprehension of nursing instructions and increase orientation in the acute care setting. However, these cues are often provided ineffectively, such as by writing too much or not making the cues portable. Alternatively, large-print statements, posted on the patient's bedside tray and within

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eye range, can help patients to remember where they are, how to call for help, and other important messages relevant to their medical condition. Thus, staff in-services are important for teaching nurses how to make appropriate written cueing systems for the particular care needs of an individual and how to implement them for maximum effects.

Rehabilitation/Skilled Nursing

The patient in rehabilitation or skilled nursing is, by nature of the medical condition that necessitated this placement, in a temporary situation that can be disorienting and disagreeable. When the patient comes from acute care, the effects of pain medications and the residual effects of anesthesia may still be contributing to increased cognitive dysfunction. If the medical condition (e.g., hip fracture) and the rehabilitation are painful, the person will not be in the best frame of mind to cooperate with therapy. In these situations, the patient's care planning is usually conducted by a team of professionals, including the physician, social worker, SLP, occupational therapist, physical therapist, and nursing staff. Therefore, the therapeutic intervention plan must address the patient's need to understand and cooperate with demands from multiple therapists. SLPs have a unique opportunity in this setting to provide consultation services to the other professionals in the form of advice about the patient's cognitive, communicative, and cueing needs. Whenever opportunities for cotreatment exist, the patient's needs will dictate the particular therapeutic routines that are undertaken. For example, if the primary focus of rehabilitation is physical recovery, the SLP can best serve the client's needs by ensuring that the physical therapist's instructions are presented in a format that the patient can understand and remember. Consultation about length of verbal commands, repetition of the same verbal command, and the use of written commands with picture supplements should be offered. Figure 8.8 illustrates examples of memory aids used for physical therapy. The objective of the consultation should be the enhancement of therapy outcomes and the most independent placement possible on discharge.

Case Report 11

Mrs. Collins, who had sustained her third traumatic brain injury, was seen in skilled nursing for rehabilitation. The SLP was impressed that her communication skills were quite functional and was going to discharge her. However, the physical therapist reported frustration that Mrs. Collins was physically strong and able to do a good transfer but did not attend to her foot placement and sometimes got the sequence of steps wrong. Mrs. Collins was otherwise ready to be discharged, and her very supportive family wanted her to live in her own home, surrounded by family members in neighboring houses. However, Mrs. Collins needed to be able to be alone for 4 hours a day and to use the bedside commode independently. The physical therapist did not know how to develop strategies to deal with the impact of cognitive deficits on physical safety, so she asked the SLP to cotreat the resident. The SLP made a cue card that listed four steps to transfer safely and then used spaced retrieval to train Mrs. Collins to read the cue card before initiating a transfer. Mrs. Collins was successfully discharged to her own home rather than having to stay in long-term care.

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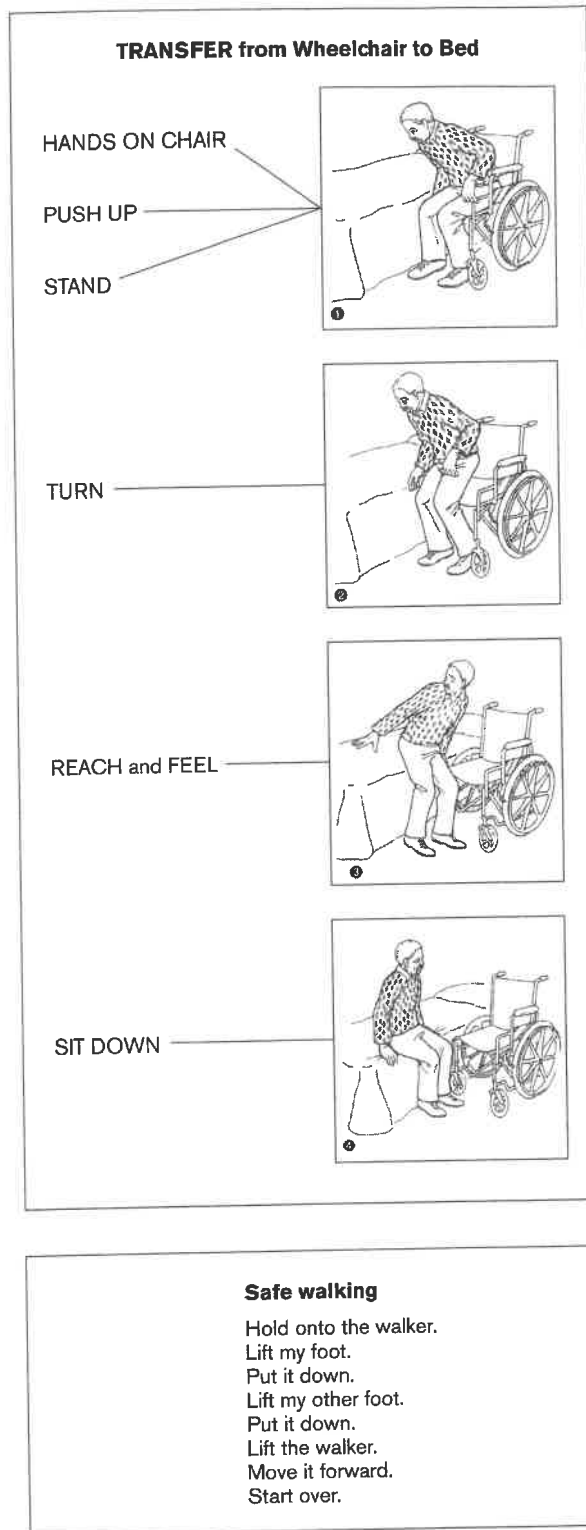


Figure 8.8. Physical therapy cue cards. (Adapted from Crabtree, J., & Crabtree, D. [1993]. *Home caregiver's guide: Articles for adult daily living*. Tucson, AZ: Therapy Skill Builders.)

WHAT IF I DON'T GET REFERRALS FOR CLIENTS WITH DEMENTIA?

In many medical facilities, SLPs spend at least 80% of their time working in the area of dysphagia. Many SLPs are simply going along with usual practice in that facility and are kept busy enough with dysphagia referrals that they do not go out of their way to look for communication-related referrals. This is understandable. However, many individuals with reduced communication abilities are then at risk for decreased activities, participation, and quality of life. As we have delineated in this chapter, the SLP's role is to work with people with cognitive-communication disorders, even if those disorders result from degenerative diseases. The SLP can educate the staff regarding the role of the SLP and can solicit these referrals. Following are some tips for doing this, based on the second author's clinical experience in a wide variety of nursing homes and hospitals:

1. Try to get one referral for a person for whom you think you can make a significant change in activities, participation, and/or quality of life. Thus, you can demonstrate that improvements can be made with one case, which can increase your credibility with the rest of the team.
2. As other team members begin to see how much an SLP can do for people with dementia, further educate them on cognitive-communication disorders and the role of SLPs. Remember to include nursing assistants and family members as integral team members who can advocate for appropriate services for people with dementia.
3. A good way to demonstrate techniques and to increase understanding of SLP treatments is to cotreat with the occupational therapist and physical therapist.
4. Another excellent way to increase understanding of treatment techniques and enhance carryover of goals is to treat within leisure activity programs. This allows you to demonstrate techniques and train activities staff and will likely increase your referrals for other residents with whom they are having difficulty.
5. An excellent way to gain acceptance of your role is to educate staff from the top down; if you get support from higher up (e.g., the director of nursing or the nursing home administrator), you are very likely to start receiving referrals for your services.

Case Report 12

An SLP started working in a nursing home where the previous SLP had worked only with residents with dysphagia or dysarthria. After a few weeks, the SLP's caseload had decreased, and she had time to screen other residents. One resident of interest to the SLP was Mr. Murphy, who sat in the hallway and spit at, kicked, punched, and called names to people walking by. The SLP spoke to the nursing staff about Mr. Murphy's problem behaviors and his lack of satisfying interactions with others. The social worker and nursing staff stated, "Why would you see him? What could you possibly do with him?" The SLP did a chart review and found that this was actually a change of condition—Mr. Murphy previously had not initiated any interaction and was very lethargic most of the time. On the basis of the ability to document this change in condition and Mr. Murphy's increased potential to participate in treatment, given his increased alertness, the SLP sought a referral from the physician. The SLP learned that Mr. Murphy's wife lived in the independent

apartments next to the facility. When she visited him, Mr. Murphy was quiet and content, but they rarely talked. Mrs. Murphy was skeptical but more than happy to have someone attempt to help her husband to communicate. The SLP went to her apartment and selected pictures of Mr. Murphy's life and family and, with his wife's assistance, made a memory wallet. Fortunately, this couple had had a tremendously interesting life together. Mr. Murphy was very pleased to read the memory wallet and converse about the topics. He told stories of living in South America, recalled his daughter who had died at the age of 18, and was proud to discuss his accomplishments as a musician. His wife sat and watched, with tears rolling down her face, as she discovered that her husband had not forgotten all these important details of their life—he just needed assistance to recall them and converse about them. Furthermore, the staff began to surround Mr. Murphy rather than avoid him, because they wanted to know more about the amazing things this man had done in his life. The problem behaviors quickly disappeared because Mr. Murphy now had a way to initiate positive interaction with many conversation partners. The memory wallet also kept his mind stimulated when he was alone. The SLP soon had such a big caseload (including many residents with cognitive-communication disorders) that she had a waiting list, and the rehabilitation company had to send in an extra SLP to help her catch up with all the referrals!

WHAT ARE THE UNIQUE FUNDING ISSUES RELATED TO DEMENTIA?

Terminology and Goal Writing for Reimbursement

Obtaining funding for rehabilitation services, particularly in skilled nursing and long-term care facilities, can be quite overwhelming. To complicate matters, there are many misconceptions about whether SLPs can be reimbursed for working with people with dementia. Although it can be challenging to obtain reimbursement for these services in some instances, it is possible. As was stated above, the OBRA of 1987 mandated communication-related service provision for residents with dementia. However, it is up to the SLP to document needs, goals, and deficits in a way that is acceptable to the local intermediary.

One important aspect of documentation for funding is the correct use of acceptable terminology. We are not going to give hard and fast rules for terminology use, because this changes across intermediaries and over time. However, there are a few constants: You must document that communication is a factor in providing services, and you must document that you provided skilled services (i.e., your services required special training and could

Reimbursable Goals

1. Client will be able to indicate meaningful information about pain and body function to staff using multimodality communication with minimal cues 90% of the time.
2. Client will make comprehensible requests for basic needs using written and visual cues with minimal staff cues 80% of the time.
3. Client will increase ability to participate in conversation/activity programs using written cues and pictures with minimal staff cues 80% of the time.
4. Client will produce comprehensible language in conversation related to basic, social, and emotional needs using written cues 90% of the time.

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5. Client will decrease occurrence of agitation and abusive verbal behavior through increased functional communication using written and visual cues with fewer than two episodes of agitation per shift.
6. Client will decrease repetitive questions related to [subject] using written cue cards with minimal to no verbal cues to fewer than two times per hour (or five times per day).
7. Client will increase recall of daily schedule using a written cue card and minimal to no verbal cues 80% of the time.
8. Client will use a memory log-book to increase recall of personal and facility information with minimal to no verbal cues 80% of the time.
9. Client will increase recall of hip precautions using a written cue card independently with greater than 90% accuracy.

not be done by someone without that training). The initial evaluation, treatment plan, and discharge paperwork must all reflect skilled speech-language pathology services.

Skilled services include the following:

- Diagnosing/assessing communication and cognitive skills
- Designing treatment programs
- Establishing compensatory skills
- Conducting task analyses to establish a hierarchy of tasks and cues to direct a client toward a goal
- Training the client and staff or family caregivers to implement a restorative treatment program (i.e., skills can improve) or a functional maintenance program
- Reevaluating the client on the basis of a change in condition (either an increase or a decrease in status)

There should be a staff member or supervisor within the hospital or rehabilitation company who can keep the SLP up to date on acceptable terminology. The *ASHA Leader* is another good resource for tips on Medicare documentation. Communication goals for people

with dementia must be written so that they reflect skilled services and address communication needs. Following are examples of a goal written to reflect skilled versus unskilled services:

- Skilled: "Client will initiate communication at the sentence level using memory cards with a photo and written sentence to social/medical/nursing needs."
- Unskilled: "Client will practice reading sentences on memory cards."

The bottom line is that in requesting reimbursement for SLP, treatment goals should never use the word *practice* and should always focus on a functional communication need.

When documenting progress from week to week or from month to month, the SLP must also show how the client is progressing and that the goals are being modified accordingly. Thus, the behavioral objectives should indicate this progression. Some examples of how to modify behavioral objectives over time include changing the level or complexity of the behavior, changing the level or types of cueing or assistance required, changing the context in which the behavior will be performed, revising the timing of stimuli and responses, and increasing the percentage of accuracy or frequency of occurrence of a behavior. Following are examples of these aspects of the behavioral objectives that can be modified.

Another important aspect of documentation in the plan of treatment is the statement of reasonable expectation for progress. As was discussed above, the SLP must identify a client's strengths as well as needs in an evaluation. This understand-

Modifying Short-Term Objectives to Show Progress in Functional Behaviors

Level of complexity of the behavior:	Level/types of cuing/assistance/prompts:	Time intervals/immediacy of responses:
Words, phrases, sentences, conversation	Minimal, moderate, maximum	Recall after 5-minute delay, 1-hour delay, 24-hour delay
Copy written words, write to dictation, spontaneously write	Tactile, verbal, visual	Respond within 30 seconds, 15 seconds, 5 seconds
Find sections in memory book, find specific information, use book independently	Context: In treatment sessions In one-to-one conversation with another resident/ staff member In group conversation/ activity	Percentage of accuracy, frequency of occurrence, number of repetitions, number of trials

ing of the client's strengths will help the SLP to state a reasonable expectation for progress. Some examples of strengths to document include the following:

- Intact auditory comprehension/ability to follow directions
- Adequate attention skills for your treatment tasks/strategies
- Ability to generalize from a structured learning environment
- Intact skills that allow the patient to compensate for specific deficits (e.g., oral reading ability)
- High level of motivation
- Preserved social skills
- Demonstrated desire to interact with others in the environment (Holland, 1998)

Appeals

Some clinicians avoid working on goals other than dysphagia goals because they fear reimbursement denials. Fortunately, clinicians around the country are reporting success in obtaining reimbursement for interventions that are designed to improve the cognitive-communicative functioning of patients with dementia across the severity continuum and in a variety of settings. This is because clinical researchers are pub-

Documentation of Reasonable Expectations for Significant Progress

- Understanding of conversational speech improved when shorter sentences with simple vocabulary were used, background noise was reduced (e.g., radio and television were turned off), and client was alerted to attend to conversation before speaking to him. This suggests that training and instruction to the client and his caregivers will help the client to understand conversation related to his medical care and social and emotional needs.
- The client displays intact reading skills, which suggests that she could benefit from use of external aids, such as written and photo cueing systems to increase her ability to follow directions in therapy, to use compensatory strategies for specific deficits and medical precautions, and to maintain attention for task completion.
- Given graphic cueing systems (written sentences and photos), the client was able to produce appropriate verbal language at the phrase/sentence level. This suggests that training the client to use these types of compensatory strategies would allow him to become a functional communicator for basic, social, and emotional needs.

lishing more reports of successful treatment strategies for people with dementia and because clinicians who have been denied reimbursement for these clients have appealed the decision with positive outcomes. In many cases, intermediaries might not be aware of effective interventions, other than dysphagia treatments, for people with dementia. Therefore, the appeals process can serve an educational function and increase reviewers' knowledge of effective treatments.

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RESOURCES

911 Medalert.com

<http://911medalart.com>

Source for medication reminder systems

Administration on Aging (AOA)

http://www.aoa.gov/prof/aoaprog/elder_rights/LTCombudsman/ltc_ombudsman.asp

Elder rights information for long-term care ombudsmen

Alzheimer's Association

<http://www.alz.org>

Alzheimer's Disease Education and Referral Center (ADEAR)

<http://www.nia.nih.gov/alzheimers>

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Alzheimer's Foundation of America (AFA)

<http://www.alzfdn.org>

The American Geriatrics Society

<http://www.americangeriatrics.org>

Attainment Company, Inc.

<http://www.attainmentcompany.com>

Picture stimuli and examples of written materials designed to support activities of daily living

Eldercare Locator

<http://www.n4a.org/locator>

Eldercare local community services

E-Pill Medication Reminders

<http://www.epill.com>

Health Professions Press

<http://www.healthpropress.com>

Materials related to Alzheimer's disease

Mayo Clinic

<http://www.mayoclinic.com/health/alzheimers-caregiver/AZ00038>

Medline Plus

<http://www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html>

National Association of Area Agencies on Aging

<http://www.n4a.org>

News for You

<http://www.news-for-you.com>

Adult literacy resources

Oregon Center for Applied Science, Inc.

<http://www.hcmarketplace.com>

Videotape and CD-ROM training materials