

# Facilitating Functional and Quality-of-Life Potential Strength-based Assessment and Treatment for All Stages of Dementia

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The number of persons with Alzheimer's disease and related dementias continues to grow in America and worldwide. There is a very high prevalence rate of residents in long-term care communities including nursing homes and assisted living communities. Typically, our long-term care communities utilize a medical model of care, which does not enable this population to achieve its functional or emotional potential. Residents with dementia can achieve quality of life and often have higher functional potential than facilitated within a medical model. This article presents an interdisciplinary model based on theoretical foundations, using the theory of retrogenesis developed by Dr Barry Reisberg, the Person-Centered first approach developed by Dr Thomas Kitwood, and the Allen cognitive disabilities theory developed by Claudia Allen. Examples of the system of implementation of the Forget-Me-Not Care Model™ developed by the author are given. **Key words:** *Alzheimer's disease, Allen cognitive disabilities theory, dementia, person-centered care, Theory of Retrogenesis*

## OCCURRENCE OF DEMENTIA

The number of individuals with Alzheimer's disease and related dementias continues to grow worldwide. Experts report that there is an estimated number of 24.3 million people who have dementia today with 4.6 million new cases of dementia every year. The number of new cases will double by 2040 in developed countries such as the United States, but will more than triple in India, China, and other countries in south Asia and the western Pacific.<sup>1</sup>

It is estimated that 4.5 million Americans have Alzheimer's disease and the number of Americans with Alzheimer's has more than doubled since 1980. This number will continue to grow. By 2050, the number of Amer-

icans with Alzheimer's disease could range from 11.3 million to 16 million.<sup>2</sup>

Dementia is prevalent in all environments. Estimates indicate that more than 7 of 10 people with Alzheimer's disease live at home, where almost 75% of their care is provided by family and friends.<sup>3</sup>

The prevalence of dementia in Assisted Living communities in the United States is significant. Estimates vary; however, a recent study conducted in Maryland revealed that 67.7% of those living in the assisted living communities studied had dementia.<sup>4</sup>

According to Dr Adam Rosenblatt, the lead author of this Maryland assisted living study, the number of individuals who have dementia in assisted living communities across the country is much greater than healthcare professionals believe. He thinks that there is a belief that residents who do not live in dementia units do not have dementia.

In fact, the rate of dementia off the dementia units is probably about the same as the rate on the dementia units. The dementia units have locked doors and higher staff-to-resident ratios [because]

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their patients may be more likely to wander and need more supervision, but there are a large number of persons with dementia on the nondementia units.<sup>5</sup>

Of course, the rate of dementia is also very high in nursing facilities. According to the American Health Care Association, dementia affects more than 67% to 77% of the 1.5 million individuals in the United States who reside in nursing homes.<sup>6</sup>

We can surmise that there is also a large percentage of home healthcare clients with dementia based upon the aforementioned estimate that 7 of 10 people with Alzheimer's disease live at home.

## TYPES OF DEMENTIA

The word *dementia* is of Latin origin meaning senseless, mad, or foolish. It is derived from a combination of de-, "out of," and mens, "mind." Dementia indicates the presence of a pathologic process causing changes in the brain that impact a person's ability to function independently. There are numerous different conditions and diseases with dementia symptoms.

Alzheimer's disease is the most common dementing disease seen in the elderly, affecting about 60% of all people with the diagnosis of dementia. Degenerative changes in the brain lead to problems with short-term memory, learning and retention of new information, problem solving, spatial orientation, and language ability. Changes in personality, mood, and behavior are very common.<sup>7</sup>

Multi-infarct or vascular dementia represents 10% to 20% of cases of dementia, and is recognizable by the presence of focal neurologic signs and a stepwise progression of symptoms. Early gait changes at onset with a history of multiple CVAs are signs that may assist in differentiating vascular dementia. Risk factors are hypertension or coronary artery disease.

Dementia with Lewy bodies accounts for 20%. The early symptoms of dementia with Lewy bodies are not memory problems, as

seen in patients with Alzheimer's disease, but impairments with attention, logical thinking, and spatial and time perceptions. There are fluctuations in memory and cognition that are not seen in other types of dementia. Within the first year of onset of dementia with Lewy bodies, the patient usually exhibits parkinsonism motor problems and visual hallucinations. Gait changes usually occur within the first year of the disease, whereas in Alzheimer's gait changes usually occur in the middle to late stages of the disease.<sup>8</sup>

Frontotemporal dementia, including Pick's disease and primary progressive aphasia, has a progressive onset and typically presents with memory loss later in the disease. Personality and behavior changes usually present first. As the disease progresses, motor skills and memory impairments arise. Frontotemporal dementia most often occurs in adults aged between 40 and 64.

Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia combine to account for 90% of individuals with dementia.<sup>9</sup>

## IMPACT OF DEMENTIA ON FUNCTION

The cognitive impairments that accompany dementia impact a person's degree of independent functioning. Cognition is the primary performance component that determines a person's level of functional performance. *Cognition* is defined as the ability to acquire, process, and apply information to regulate our behavior. Aspects of cognition include, but are not limited to, attention, problem solving, memory, and executive functions. A person's cognitive status directly relates to the level of function one can achieve in daily activities. If there is a deficit in any area of cognition, a person will often experience functional impairment. Therefore, it is imperative that professionals competently assess a person's cognition to identify highest ability to function before creating a treatment or care plan.

Unfortunately, in my experience, I have found that the cognitive assessment performed by healthcare professionals such as therapists or nurses for this purpose is often inadequate. Typically, the cognitive assessment is not based on any clear assessment criteria, or the assessment is too reliant on a resident's verbal skills. With moderate or severe dementia, verbal tests may bottom out prematurely, leaving the rater as unable to identify cognitive status once verbal skills are diminished. Therefore, I highly recommend using functional methods of cognitive assessment to circumvent the verbal skill requirement, in order to identify true best ability to function. These recommended assessments will be discussed later in this article.

### IMPACT OF DEMENTIA ON QUALITY OF LIFE

Dementia often has a direct impact on a person's quality of life. *Quality of life* is defined and measured in a variety of ways for different populations and environments. Kane and colleagues, building on the work of M. Powell Lawton,<sup>10</sup> identified the following domains of long-term care quality of life: emotional health, physical health, functional status, comfort and security, social function, and self-worth or personal agency.<sup>11</sup>

The late Dr Thomas Kitwood, University of Bradford, UK, explored what he referred to as well-being. Dr Kitwood developed the person-centered care approach to dementia in which he places the person with dementia as the focal point of caring. The professional is asked to work to honor the individual person at all stages of the dementia process. He defines *person-centered care* as "Care is envisaged as being much more than that of meeting basic physical needs; it is a matter of attending to the whole person, of enabling each individual to make the fullest possible use of his or her abilities and to remain a social being."<sup>12</sup>

Kitwood emphasized identifying and understanding caregiver behavior as it impacts the well-being of persons with dementia.

He described well-being and ill-being as follows:

A person's psychological state with indicators of well being: Assertiveness; bodily relaxation; sensitivity to the emotional needs of others; humor; creative self-expression; helpfulness; initiating social contact; affection; self-respect; expressing a full range of emotions; and acceptance of others who also have dementia. Indicators of ill-being are: unattended sadness or grief; sustained anger; anxiety; boredom; apathy and withdrawal; despair; physical discomfort or pain.<sup>12</sup>

He went on to suggest that these indicators of ill-being should be identified by caregivers as these behaviors interfere with quality of life for persons with dementia.

Another important term described by Kitwood is "personhood." He defined *personhood* in this way: "The so-called cognitive abilities are only a part of the totality of our human functioning. . . . Personhood, in the full sense, involves a great deal besides cognition, for example: feelings, action, belonging, attachments to other persons, and identity."<sup>12</sup>

He suggested in his work that there is an old culture of care and a developing new culture. They are described as follows.

#### Old culture of care

The old culture of care views the emphasis of dementia caregiving as managing safety, meeting basic needs, and giving physical care. Staff often has few abilities, inspirations, or qualifications, and doctors are seen as possessing the reliable, valid, and relevant knowledge. The view of degenerative dementias is seen as devastating illnesses in which personality and identity are progressively destroyed. It is important to have a clear understanding of a person's impairments, especially those of cognition.<sup>12</sup>

#### New culture of care

The new culture of care views dementia care as one of the richest care fields, demanding resourcefulness, knowledge, and flexibility. It views the caregiving as not only meeting basic needs and addressing safety and

physical care, but emphasizing maintenance and enhancement of personhood. Caregivers and insightful practitioners are seen as the people who possess the most reliable, valid, and relevant knowledge. Dementia is seen as a form of disability, and the quality of care is crucial to how a person with the disease fares. It is important to have a clear understanding of a person's abilities, tastes, interests, values, and forms of spirituality.<sup>12</sup>

While it is now recognized that the new culture of care is one that must assess, emphasize, and monitor quality of life, there are challenges. A recent study supported by grants from the National Alzheimer's Association sought to evaluate the effectiveness of current quality-of-life instruments used in long-term care including those that primarily utilize interview methods and those that utilize observation methods. The study concluded that there are many measures that currently exist to provide windows to the quality life of long-term care residents with dementia, but there is no single instrument that can claim superiority and indeed no instrument adequately captures the broad canvas of quality of life. However, the study states that given the progressive, terminal nature of Alzheimer's disease, being able to capture a clearer image of quality life throughout the illness will help guide treatment and, ultimately, improve the experience of persons with the disease, their families, and those who provide their care.<sup>13</sup>

The Centers for Medicare and Medicaid Services addresses the relationship between the culture of care in a long-term care community and functional and emotional potential of a resident as described in this statement:

Most residents' value being able to take care of themselves. It is important that nursing home staff encourage residents to do as much as they can for themselves. In some cases, it may take more staff time to allow residents to do these tasks than to do the tasks for them. Residents who still do these basic daily activities with little help may feel better about themselves and stay more active. This can affect their health in a good way. When people stop taking care of themselves, it may mean that their

health has gotten worse. The residents' ability to perform daily functions is important in maintaining their current health status and quality of life. . . .<sup>14</sup>

As discussed, dementia can impact function and quality of life but it does not mean that both have to be stripped away as the disease progresses. Kitwood has stated that having dementia does not, in itself, entail a loss of personhood. In fact, a person with dementia can still have a high level of well-being, despite the presence of cognitive impairment.<sup>12</sup> On the basis of my experience, I would concur. There is a tremendous amount of functional and emotional potential that often goes unrealized because of the many barriers that currently envelop our long-term care system. I will now address some of these "potential inhibitors" and later will discuss a highly successful dementia care model that embodies Kitwood's person-centered concepts and strength-based approach to assessment and treatment.

## POTENTIAL INHIBITORS

### Dementia paradigms

The word *paradigm* refers to a "prevailing belief." Through my work as a dementia consultant and trainer, I have found the following to be the "prevailing beliefs" and descriptions used by many healthcare professionals and caregivers who serve those with Alzheimer's disease and related dementias.

- A person with dementia is in the midst of loss and regression—they are often defined as "confused," "pleasantly confused," and hopeless.
- Depressed—I have often heard, "It is normal for this person to be depressed. . . they have dementia."
- Behavior problems are normal: I have often heard, "They act that way (behavior issues such as agitation and wandering) because they have Alzheimer's—there is nothing that we can do."
- Dependent: I have often heard, "They can't do anything anymore—they have Alzheimer's."

These beliefs become embedded in the goals that we set for these individuals. If our belief system almost exclusively encompasses loss and despair, how could we possibly leap to goals that reflect strengths and promote emotional well-being? Negative outcomes and indicators of ill-being are often perceived as “normal” for a person with dementia, and therefore the staff may ignore these problem areas, taking a hands-off approach to issues, such as behaviors, functional loss, depression, and low activity involvement.

This focus on disability and indifference to dementia behaviors will not enable the person with dementia to achieve his or her functional and quality-of-life potential. Instead, we must convert our thinking to new paradigms. I present the following:

- abilities remain at every dementia stage, and these abilities can be directly converted to maximizing function and well-being;
- successful social and leisure activity engagement is possible at every stage of dementia, and this can positively impact activity levels and mood;
- behaviors associated with dementia such as wandering, agitation, and resistance to care are not normal—they are usually an expression of a problem and ill-being, and they can be minimized with a quality dementia program; and
- well-being can be realized throughout every stage of dementia

### Medical model of care

Another “potential inhibitor” for a person with dementia in long-term care is the medical model that often governs this environment. What’s in a name? Everything. The very fact that we call the long-term care community a “nursing home” signifies the emphasis of care. In a medical model environment, the resident is often referred to as a patient. The word *patient* is a noun meaning “a person who is being treated for some illness or injury.” Its origin is the Latin verb *pati*, meaning “to suffer or endure.” Our language reflects our be-

liefs and conveys our approaches to care. This term clearly identifies the resident as a person who is ill and suffering and therefore often leads to caring for the medical symptoms at the expense of the whole person.

While long-term care in nursing homes offers many people with Alzheimer’s disease the best duration of survival,<sup>15</sup> the institutional setting and education of staff often foster the traditional medical model of care, in which the individual’s right to maximum autonomy is suspended in exchange for care and reduced responsibility. Residents in long-term care are not patients in a medical situation all day; they are residents most of the time.<sup>16</sup> However, those who reside in long-term care environments often find their quality of life placed as a low priority, lagging far behind caring for their medical needs. Many health-care workers think that if patients are dry, fed, and free of injury, they do not have any other needs.<sup>17</sup> Individuals who suffer from dementia gradually become dependent on caregivers to adapt life and all of its wonderful activities to their current ability level. The will to live withers if the person no longer feels a sense of purpose and enjoyment from successful engagement in valued roles and activities. The goals of the caregiver and all staff must include enabling this individual to achieve and maintain quality of life. If goals are based solely on the medical model of caregiving, the person inside the “patient” is forgotten. Challenging behaviors appear, and function and activity participation decline. This leads to dramatically increased burden on the caregiver, which may lead to higher facility costs.

In contrast to the medical model, a social model of care is one that emphasizes caring for the whole person as in Kitwood’s person-first approach. This new model of care and culture change are being advocated for in long-term care and supported by the Pioneer Network ([www.pioneernetwork.net](http://www.pioneernetwork.net)) to ensure that we address the many needs of the whole person, not just the medical needs of the patient. This model is beginning to demonstrate positive outcomes as described by the Pioneer Network and as seen in my

**Table 1.** Fundamental differences between a medical model and social model of care

| Medical model   | Social model   |
|---|--|
| Emphasizes caring for medical conditions                          | Emphasizes caring for the whole person including emotional, social, and spiritual needs              |
| Restricts resident/family choice                                  | Encourages resident choice and family involvement  |
| Trains staff to address medical needs                             | Trains staff to relate to the needs of the whole person  |
| Environment designed to support medical needs                     | Environment designed to foster maximum function and well-being                                       |
| Medical model outcomes  | Outcomes that include well-being   |
| Views the living environment as a temporary place to recover      | Views the environment as “home”  |
| Medical language (ie, patient, diagnosis)                         | Social model language (ie, Who is the resident and what are his or her holistic needs?)              |
| Grouped and identified as a homogenous group by medical condition | Recognized as individuals and grouped as peers according to cognitive, social, and functional levels |

experience as I will share in our case study. See Table 1 for a comparison between these 2 models.

**FUNCTIONAL COGNITIVE ASSESSMENT TO FACILITATE FUNCTIONAL POTENTIAL**

In 2000, I developed the Forget-Me-Not Care Model™ to help persons with dementia to achieve their highest functional and quality-of-life potential. This model uses an interdisciplinary approach in which team members work together, using common frame of reference, to help residents achieve goals that represent their individuality and preferences. Concepts from Kitwood’s Person-Centered Care, Claudia Allen’s Cognitive Disabilities Model, and Barry Reisberg’s Theory of Retrogenesis were adopted.

At every stage of dementia, abilities remain. Dr Reisberg describes dementia stages and correlates these stages to developmental age. As with children who are in a process of development, varying degrees of cognitive and therefore functional abilities are present. The same is true for a person with Alzheimer’s disease or a related dementia. As with children, the senior with dementia will require the caregivers to adapt or simplify the cognitive de-

mand of the activity to match the ability level of the person.

As previously discussed, it is impossible for a person with dementia to achieve his or her potential unless his or her cognitive status has been understood. The degree of independence that one can achieve and the necessary cognitive activity adaptations must be identified through a functional cognitive assessment.

There are many cognitive assessments tools available and widely utilized such as the Mini-Mental State Examination; however, for the purpose of creating a care or treatment plan to maximize a person’s functional potential, the MMSE is not the best choice. Instead, I utilize 2 functional cognitive assessments, the Adapted FAST (Functional Assessment Staging Tool), based upon the Theory of Retrogenesis, which I have found to be competently administered by most healthcare professionals with minimal training. We also use the Allen Battery, on the basis of the Allen Cognitive Disabilities theory. This battery of assessments is most often administered by an Occupational Therapist, or Speech Language Pathologist and Physical Therapist, with extensive training. Each of these assessment tools identifies a person’s degree of cognitive ability through functional performance through either subjective or objective measures.

The Theory of Retrogenesis, developed by Dr Barry Reisberg, hypothesizes that those with Alzheimer's disease experience neuron death and loss of associated functions in roughly the reverse order that the cells and the functions developed from infancy to adult. It is somewhat of a reverse developmental theory.<sup>18</sup>

There are several cognitive assessment tools that Dr Reisberg designed to determine a person's dementia stage including the Global Deterioration Scale, the Brief Cognitive Rating Scale, and the FAST. Kim Warchol and Caroline Copeland created an Adapted FAST scale that further differentiates functional hallmarks at the lower end of the scale. These assessment tools are all rather quick and easy to administer and give a rather broad definition of dementia stage.

The Allen Cognitive Disabilities theory identifies functional abilities at every stage of the dementia process. It enables us to use cognitive activity analysis skills to adapt all activity to the current level of the person.<sup>19</sup> Activity adaptation facilitates greater functional independence and well-being for the person with dementia.

Claudia Allen created the Allen Battery including assessment tools such as the Routine Task Inventory, Allen Cognitive Level Screen, often identified as the leather lacing test, and the Placemat test, which is part of the Allen Diagnostic Module. These tools require advanced training to administer and score competently and will identify someone's cognitive performance level in a much more specific sense than the tools developed by Dr Reisberg. The patient is asked to engage in a specific task, and the assessor will be able to identify what Allen Cognitive Level and Performance mode the person is functioning at based on his or her performance of the activity. The person is asked to perform both procedural and working memory activities. The Placemat test, for example, is designed to assess working memory as it is an unfamiliar activity. On the basis of the results of this test, the assessor will be able to predict how a person will function in other unfamiliar activities

such as learning to use a walker or adaptive equipment. Table 2 demonstrates the approximate relationship between these assessment tools with a brief description of the dementia stage and key remaining abilities.

I must reiterate that one of the crucial factors of our model is that we proceed with assessment, observation, and treatment from the perspective of identifying and facilitating remaining abilities. We try to objectively identify strengths and then adapt an activity to enable persons with dementia to use these strengths while we compensate for their deficits.

When I teach a course on our assessment and treatment approach, I often start the class by acting the part of a familiar resident with moderate to advanced dementia. I walk about the room, collecting pieces of paper, perhaps stopping for a moment to fold and then pocket my collection, and then move on to a door in which I try to exit asking how to get home. When I am approached and redirected by a staff person I follow. I then ask my students to describe the person they just observed. I am often provided with descriptors such as "confused," "wanderer," and "lost." I then tell them another way that this person could be described on the basis of the perspective of seeing the abilities the person just demonstrated. The person showed us that they can use their hands to pick up and manipulate objects (the paper collecting and folding), the person can still walk without need for physical support, the person can still comprehend and follow a 1-step verbal direction, and the person can still sustain their attention to an activity for at least 1 minute. I almost always see my class smile with amazement.

Typically therapists are educated in a disabilities framework and therefore taught to see disabilities. We then proceed with rehabilitation or remediation approach to fix these deficits. This approach is not effective if the person's deficits in function or safety are being caused by a progressive, irreversible dementia. In this case, the therapist must see abilities and use a habilitative or

**Table 2.** \* Correlation of Cognitive Assessments

| Allen cognitive level   | Adapted FAST score and approximate developmental age correlation | MMSE score  | Brief description of dementia stage  | Key remaining abilities  |
|-------------------------|--|-------------|--|--|
| 4.4, 4.6, 4.8           | 4 = 8- to 12-year-old  | 20 (±4.6)   | Mild: Decreased ability to perform complex tasks or Instrumental Activities of Daily Living (IADLs)                            | Selects own clothing; good activity of daily living (ADL) quality—usually independent in basic ADLs  |
| 4.0, 4.2                | 5 = 5- to 7-year-old   | 14.4 (±4.8) | Moderate: Requires assistance for choosing proper clothing; needs assistance for quality of ADL work                           | Able to sequence self through the steps of a familiar task such as putting on own clothing—usually supervision or minimum assistance in basic ADLs |
| 3.6, 3.8                | 6 a, b, c = 4-year-old   | 11.0 (±5.1) | Moderately severe: Improperly putting on clothing without assistance or cuing; needs sequencing assistance                     | Can follow 1-step verbal commands to participate in activities—usually moderate assistance in basic ADLs   |
| 3.2-3.4                 | 6 d, e = 2- to 3-year-old  | 6.3 (±3.2)  | Moderately severe: Urinary or fecal incontinence; greater difficulty following cues requiring tactile or hand-over-hand cueing | Can follow 1-step commands with verbal, visual and tactile cues—usually moderate to maximum assistance in basic ADLs                               |
| 2.2, 2.4, 2.6, 2.8, 3.0 | 7 = 1-year-old   | 0.3 (±0.8)  | Severe: Ability to speak limited and diminishing ambulation skills   | Can stand and walk, although diminishing; can make gross motor movements—usually maximum assistance in basic ADLs                                  |
| 1.0-2.0                 | 8 = Infant   | 0           | Severe: Mute and ambulation ability lost   | Is aware of environment; can still respond to sensory stimulation—usually total assistance in basic ADLs   |

\*Adapted from Allen<sup>19</sup> and Reisberg.<sup>20</sup>

consequences approach to facilitate improvement and highest level of function.

When working with a person with Alzheimer’s or a related dementia, it must be understood that this person will live with ongoing effects from their disease process.

Therefore, it is important for the clinician to have an understanding of the various models available. The consequences and rehabilitative approach are both recommended to maximize functional loss due to Alzheimer’s or a related dementia.



We first compare and contrast the remediation model and the consequences model. Allen provides these definitions:

Remediation aims at reducing signs and symptoms and assumes that such a reduction will generalize to a reduction in difficulties in doing many or all functional activities. Many early rehabilitation conceptual models were framed in this view of change. The consequences model is driven by losses of function that are a result of a disease process or injury. Consequences are residual limitations that remain after medical treatment is finished or the natural healing process has stabilized. The treatment goals . . . are designed to match the demands of the activity to the patient's remaining abilities. The burden of living with the consequences is reduced by rehabilitation therapists who maximize the patient's remaining abilities.<sup>19</sup>

Next we make a clear distinction between the rehabilitation approach and habilitation approach.

*Rehabilitation* has been defined as "A combination of physical, occupational, and speech therapy; psychologic counseling; and social work directed toward helping patients maintain or recover physical capacities."<sup>21</sup> In contrast, habilitation is an approach in which the clinical team does not seek to recover capacities but instead to maximize a person's remaining capacities.

I have found great benefit in the interdisciplinary team members using cognitive assessment instruments, which correlate well and are derived from a functional frame of reference. In the Forget-Me-Not Care Model<sup>TM</sup>, we educate personnel such as a nurse to administer the adapted FAST to provide a general idea of dementia stage in order to establish highest ability to function and to generate a corresponding plan of care. In addition, other team members such as activity staff are trained to deliver care approaches that match the identified stage of dementia as a method of simple activity adaptation. Of course, the interdisciplinary team is instructed to engage in ongoing dialog in order to communicate when and if the corresponding approaches are not facilitating the outcomes desired.

This may indicate the need for additional evaluation.

Individuals with dementia are often able to be served by one or more of the therapy professionals. Because a person with dementia is often complex, the care team requires the advanced assessment and treatment knowledge of the therapist to help identify highest ability to function and approaches and strategies to elicit remaining abilities. For example, one of our residents presented as maximum assistance in activities of daily living (ADLs) and appeared to be in advanced dementia. As many elderly she also had physical deficits from another condition. Therefore, she also required physical assistance for transfers and ambulation. She also had impaired verbal communication skills and difficulty processing verbal commands and would occasionally become resistive to care. The nurse was unable to identify her best ability to function because of these other deficits and therefore she did not immediately achieve her full potential.

The entire therapy team intervened. The therapists used the Allen Battery to identify her cognitive level (which was 3.2/3.4) and also completed an assortment of other assessments. Collectively the team agreed that with her current cognitive status she should be able to perform much higher than she currently was but her communication and behavior challenges overshadowed and masked her remaining abilities. And, the physical deficits just clouded the picture even more.

The therapy team created goals that matched the performance level to her cognitive level. They found that the resistive behaviors were often a response to not understanding what was to occur, because of her communication challenges. The therapists learned that just as many individuals who function at this Allen level, her ability to comprehend the spoken word alone was impaired. And her attention to task was very poor. However, when approached slowly from the front with eye contact gained, followed by the introduction of simple and slow 1-step verbal directions with tactile and visual cues, she was highly participatory. Her

functional status dramatically improved for basic ADLs, such as grooming, toileting, and eating, and for tasks such as transfers and ambulation. Nursing, CNAs, and activity staff was now able to successfully communicate with her on a regular basis.

Therapists have another opportunity to serve people with Alzheimer's and related dementias. We can develop a maintenance program for a person who has a progressive disease such as Alzheimer's disease or a related dementia. It is considered a covered skilled therapy service to develop a maintenance program to prevent or minimize deterioration that a person with a progressive decline might otherwise experience. See the guidelines below.

The Medicare Benefit Policy Manual (Pub 100-02, Chapter 15, Section 220 & 230) describes skilled therapy, reasonable and necessary, medical necessity, and covered therapy for the development and training of a maintenance program.

*D-maintenance Programs. . .*

*Evaluation and Maintenance Plan without Rehabilitative Treatment.*

*After the initial evaluation of the extent of the disorder, illness, or injury, if the treating qualified professional determines the potential for rehabilitation is insignificant, an appropriate maintenance program may be established prior to discharge. Since the skills of a therapist are required for the development of the maintenance program and training the patient or caregivers, this service is covered.*

*Example. The skills of a qualified speech-pathologist may be covered to develop a maintenance program for a patient with multiple sclerosis, for services intended to prevent or minimize deterioration in communication ability caused by the medical condition, when the patient's current medical condition does not yet justify the need for the skilled services of a speech-language pathologist. Evaluation, development of the program and training the family or support personnel would require the skills of a therapist and would be covered. The skills of a therapist are not required and services are not covered to carry out the program.*

**INCORPORATING LIFE STORY TO FACILITATE FUNCTION AND QUALITY-OF-LIFE POTENTIAL**

Many experts believe that it is important to engage a resident with dementia in meaningful activities that represent their individuality to maximize quality of life.

Once institutionalized, the patients should participate in programs that promote a reasonable amount of stimulation while maintaining their routine. Nurses and aides should be acquainted with the patient's biography, so they see him or her as a unique person with a former life, occupation, and history rather than simply as a confused aged individual. They should treat the patient with warmth and affection. Clinicians must address the patient's autonomy, social contacts, comfort, and preferences. . . . Even if severely advanced, clinicians can still evaluate the patient's quality of life by observing nonverbal clues such as smiles, groans, and other behaviors.<sup>22</sup>

In our model we begin by gathering extensive information about each resident, using a Life Story Assessment. Residents and their families are asked to answer a detailed questionnaire that inquires about the person's background, interests, routines, and preferences. The resident's story is shared with the interdisciplinary team. Team members are required to integrate this information into the resident's plan of care. For example, if a resident indicates that he prefers a bath over a shower and the preferred time to bathe is in the evening, the person creating the CNA assignment sheets will transfer this personal data to the CNA's assignment sheet. Food likes and dislikes, activity preferences, and times the person prefers to rise in the morning and go to bed at night are all identified and honored in this individualized model of care. A partnership between the staff, resident, and family is formed preadmission and continued throughout each and every day. The community is expected to conform to the resident, and the resident is not asked to conform to the community.

Gathering the life story of a person with dementia is important for several reasons.

First, experts state that long-term memory is preserved longer than short-term memory in Alzheimer's and related dementias. Mendez and Cummings state, "There is relative preservation of procedural memory or the learning of motor tasks until the late stages of the illness. . . ."22 Therefore, we can facilitate a greater level of function when we tap into a person's long-term or procedural memories, instead of introducing something new.

Another benefit to integrating a person's life story is that familiarity may facilitate greater motivation and therefore higher function. Claudia Allen suggests that the level of activity participation and function may be related to motivation for a person with cognitive disability. She states,

The patient must agree with the meaning and purpose of the activity. When a therapist imposes an activity selection on to a patient, motivational explanations are valid reasons for poor performance. The evaluation of ability/disability is based on the assumption that the individual's performance is the best of his or her abilities. That assumption cannot be sustained when the activity lacks meaning and purpose for the individual. Therapists often need to be very resourceful to suggest activities that will elicit the cooperation of cognitive disabled people.<sup>19</sup>

In my experience, I have found a person's attention and performance to be greater throughout the stages of dementia if activity presented is familiar and meaningful to the person. In addition, I have found overall acceptance of care and a new living environment to be markedly better when the person's individuality is honored. Therefore, care plan and treatment plan goals and approaches should always incorporate the person's individuality in order to yield the greatest results.

## CASE STUDY

As stated previously, it is the job of the interdisciplinary team to obtain and honor the resident's life story in all care plans, goals, and approaches. In addition, the interdisciplinary team is responsible for simplifying activities

to match the abilities and deficits for the person's current dementia stage, as defined by the functional cognitive assessment.

I have implemented the Forget-Me-Not Care Model™ into various long-term care communities. One of the communities is located in Creve Coeur, Miss, called Parc Provence. This community opened in 2004 as a 120-bed long-term-care community serving seniors with various degrees of memory impairment. The program was implemented by the interdisciplinary team as follows.

### Preadmission

The community relations person shared the care model philosophy of incorporating personhood and discovering remaining abilities to maximize function and quality of life with prospects, their families, and the professional community. Prospects were provided with the Life Story Assessment Questionnaire and promised that the information gathered would be used to develop the plan of care. Tangible examples were provided for each family.

A preadmission assessment was often performed in which the adapted FAST was administered by a trained team member. Once the results were obtained and combined with other elements of function, family was provided with preliminary information regarding the prospects-projected level of independence and care strategies that would be employed to facilitate this ability level.

### Admission and ongoing

The new resident was introduced to the community staff not as a medical chart but as a person. Once the new resident moved into the community, a procedure required nursing and CNAs, food service director, activity director and staff, and therapy team to read the resident's Life Story. This information was then used by each of these team members in the design and implementation of the individualized plan of care. Our food service director, for example, read the resident's dining preferences

including food and drink likes and dislikes and time of day the person prefers to eat. The food service director then met with the resident and family member to discuss how these preferences could be woven into the general meal plan for the household the resident resided in and how specific food preferences such as a granola bar for breakfast could be met. In some cases, families agreed to bring in the boxes of granola bars and staff was educated to offer this to the resident for breakfast instead of the full breakfast.

The resident's activity program was also developed around their preferences. The activity likes and dislikes of the collective group of residents in a household were analyzed (the Forget-Me-Not Care Model™ software program has a report to perform this action). These activities were then incorporated into the monthly group activity calendar. As the interests or group of residents changed month to month, so would the calendar to reflect any activity preference changes. In addition, each resident had a resident profile kept in a central location that informed caregivers of the resident's interests and specific comments about these interests. The CNAs, activity staff, housekeepers, and others understood that it was their job to read these resident profiles and to engage the resident in a spontaneous activity as able and desired. For example, if a housekeeper entered the household with the goal of cleaning the dining room, he or she was encouraged to invite a resident who identified light housekeeping chores as an activity preference, to help out. It was not uncommon for me to walk into a household and see our housekeeper holding the vacuum cord while the resident vacuumed the dining rug. Similarly, it was not uncommon for me to see the CNA partnering with a resident to make coffee, clear or set tables, and do laundry. Records of spontaneous activity engagement were kept along with the resident profiles. Staff was required to document this activity participation.

Activities offered for our dementia population were very normalized because our philosophy is that almost any activity can be

adapted to a level of simplicity, which will facilitate successful participation. As previously stated, residents frequently engaged in spontaneous activities such as housekeeping and laundry. Residents also engaged in valued activities such as sitting in an easy chair to watch their favorite sports team on television, socializing in the dining room, or relaxing on the sun porch. Our residents also participated in a robust structured group activity program that included activities such as gardening, arts and crafts, music programs, puzzles, current events, and card club. I would venture to guess that the above-named activities are those you would find in your daily life. That is the goal of our Forget-Me-Not Care Model™. Our model encourages life in a long-term care environment to mirror life at home. This is accomplished by knowing who each resident is and incorporating this into their daily life, and by knowing their cognitive capacity to simplify the activities for their success.

Our nursing team was trained to acknowledge the needs of the whole person. Our nurses certainly were the experts in providing medications, medical care, or treatments, but in addition, the team was also expected to engage the residents in activities. And, the team was taught to use the Life Story and adapted FAST information to create its care plans. For example, if a resident was assessed at adapted FAST stage 6, it is unlikely that the person will have the cognitive ability to use a call system. Therefore, the nursing staff was required to create an alternate plan to meet the resident's needs and to keep the resident safe. Often this plan included adapted strategies for cognitive ability level as well as incorporation of valuable personal daily routine information such as toileting routine, night time habits, etc.

Our CNAs provided the majority of the ADL care. However, the CNAs were educated how to deliver approaches that matched the activity simplification needs of each resident. We had high CNA staffing ratios so that the staff was afforded the extra time to cue the resident with moderate to moderate/severe

dementia through the steps of simple ADLs such as brushing teeth or washing face and hands. ADLs such as grooming and eating are long-term, procedural memory activities that a person at this cognitive level can still be very participatory in and very successful, with extra time and correct cueing.

Another important component for the success of our model is a peer-to-peer living environment, where residents are grouped with others with similar care needs and cognitive levels. This is in contrast to an aging in place model. There are benefits to both models; however, I have found that because there are such differences between the stages the resident will benefit most from living with peers. Many aspects of care and the environment will change for the different dementia stages. For example, CNA staffing ratios will need to be higher on a household for persons with moderate to moderate/severe dementia versus those with mild dementia because it takes more time to deliver the care for the more advanced person—if you treat the ADL as a valued activity and do not do the task for the person.

It is helpful to have dedicated CNAs and activity staff assigned to a household so that they can become an expert in that level of dementia care. We ask a lot of our CNAs and activity staff and often they do not come to us with much dementia education. For each level of dementia, the team members need to learn a specific set of skills including communication techniques, behavior prevention and management strategies, activity adaptation approaches, and safety procedures. Therefore, to help these team members be successful, we can assign them to one level of dementia care and coach them to competency in this level before ever asking them to learn another level of care.

Also, activities will differ greatly at the different stages of dementia. Consider how activities are different for an infant, compared with a 2-year-old, compared with a 6-year-old, and compared with a teenager. There are different activity supplies used, different degrees of cognitive complexity of the activity, differ-

ent degrees of physical challenges associated with the activity, and different group sizes to encourage successful participation. As stated earlier, the dementia stages correlate to these different developmental ages. We can then understand what a disservice we do when we place residents in various stages of dementia in a large group together and provide one activity person to lead this group. Imagine 1-day care worker or teacher with 30 children ranging in ages from that of an infant to that of a teenager. What would that activity experience look like? How would the children behave? How would the staff person feel?

Once again we must reflect on the importance of understanding and honoring the collective group as a group of individuals. These individuals should not be looked at in the paradigm of disabled and unable to achieve anything greater than sitting for a moment or 2 in a group before crying out, or walking for the exit door. These individuals have real potential to engage in a meaningful activity with success. It is the burden of the facility to provide residents with opportunities for success, not failure. This requires separating residents into different peer groups for activities, adapting the demands of the activity for their peer group, and providing the proper amount of staff on the basis of the needs of the resident.

The activity program we provided at Parc Provence was very robust, and we utilized a higher than average number of activity staff to deliver the program. Individuals with dementia often thrive on routine and structure as with disease advancement it becomes difficult to structure their own day and to initiate activity and socialization. This, however, should never be mistaken for the inability to socialize or engage in activities. The person usually needs a little encouragement and cueing, and you will facilitate significant social and activity participation.

Finally, our model encourages a lot of eating and drinking throughout the day. The activity calendar at Parc Provence and our other communities is filled with activities including food and drink offerings. We have been able

to show reduced incidence of weight loss and supplement use in our dementia population by:

- Offering activities with food and drink frequently throughout the day such as a daily social event, snack after exercise, etc
- Providing a home-like, small dining environment and limiting the unnecessary noise
- Incorporating resident preferences as much as possible
- Training the staff how to cue and encourage the person's maximum level of function instead of feeding the person prematurely
- We do not accept weight loss and supplement use as inevitable if a person has dementia. Instead, we monitor consumptions and weight loss. If we see a negative trend, we ask "why?" Whenever possible, we look at all of the potential reasons for a decline in intake and we introduce the appropriate interventions to try to reverse this trend before we place the person on a supplement.

The outcomes for the Forget-Me-Not Care Model™ have been excellent. Dr Carr, the Medical Director of Parc Provence, stated this:

The activities based model of care is ideal for a long term care facility that focuses on dementia. The "Forget-Me-Not" program has definitely made a positive impact on our patients at Parc Provence. Offering a wide panel of activities along with those of specific interest to our residents (an individualized activity plan) not only results in a high incidence of participation, but enhances their quality of life. Although we do not yet have a randomized trial to show efficacy, my clinical impression is that this activity program has decreased our need for behavior medications, socialization and appetite stimulation resulting in a very small number of residents with weight loss, along with other positive health

outcomes such as a decrease in contracture and pressure sores for those with moderate to severe disease.

**SUMMARY**

I have worked in long-term care for many years and, unfortunately, I have worked in many environments governed by a medical model. I can say unequivocally that a quality social model dementia program, such as The Forget-Me-Not Care Model™, can be highly effective and achieve many tremendous outcomes. While I have not performed a formal study, I have reviewed various data reports. The results of this model have yielded

- lower than average incidence of behavior problems;
- much lower number of residents who experience weight loss in comparison with the average;
- much lower use of supplements in comparison with the average;
- very high level of activity participation for person's with mild, moderate, and moderate/severe dementia; and
- excellent staff retention.

Most importantly, I have borne witness to individuals with dementia in a long-term care community living a vital and happy life each and every day. I have seen families respond to the promise of this model of care first with disbelief and then with tears of joy. Our seniors deserve this type of care. They must be honored and revered for the person that they still are. A diagnosis of Alzheimer's or related dementia does not provide us with an excuse to overlook their emotional and spiritual needs. It is time for all long-term care communities to adopt a social model that facilitates resident ability and assures maintenance of vitality and personhood.

**REFERENCES**

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1. The Alzheimer's Association. Alzheimer's Association Research News. Available at: <http://www.alz.org/News/overview.asp>. Accessed December 30, 2005.

2. Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer disease in the U.S. population: prevalence estimates using the 2000 census. *Arch Neurol.* 2003;60(8):1119-1122.

3. Hebert LE, Scherr PA, Bienias JL, Bennett DA, Evans DA. Alzheimer disease in the U.S. population: prevalence estimates using the 2000 census. *Arch Neurol*. 2003;60(8):1119-1122.
4. Rosenblatt A, Samus QM, Steele CD, et al. The Maryland Assisted Living Study: prevalence, recognition, and treatment of dementia and other psychiatric disorders in the assisted living population of central Maryland. *J Am Geriatr Soc*. 2004;52(10):1618-1625.
5. Kaplan A. High rates of dementia, psychiatric disorders found in assisted living facilities. *Psychiatr Times*. 2005;22:3.
6. Mathews FE, Dening T. Prevalence of dementia in institutional care. *Lancet*. 2002;360:225-226.
7. Mendez MF, Cummings JL. *Dementia: A Clinical Approach*. Philadelphia, Pa: The Curtis Center; 2003.
8. Staples S, Lewis C. Dementia: differentiation and rehabilitation strategies. *Advance for PTs & PTAs* 2003;14(12):6-7.
9. Souder E, Chastain JR, Willimans RD. Dementia in the new millennium. *Medsurg Nurs*. 2002;11:61-69.
10. Lawton MP. A multidimensional view of quality of life. In JE Birren, JE Lubben, JC Rowe, DE Deutchman, eds. *The Concept and Measurement of Quality of Life in the Frail Elderly*. New York: Academic Press; 1991:3-27.
11. Kane RA, Kling KC, Bershadsky B, et al. Quality of life measures for nursing home residents. *J Gerontol Med Sci*. 2003;58A:M240-M248.
12. Kitwood T. *Dementia Reconsidered: The Person Comes First*. Buckingham, UK: Open University Press; 1997.
13. Sloane PD, Zimmerman SD, Williams CS, Reed PS, Karminder SG, Preisser JS. Evaluating the quality of life of long-term care residents with dementia. *Gerontologist*. 2005;45:37-49.v
14. MedQIC (Medicare Quality Improvement Community). Activities of daily living. Available at: <http://www.medqic.org>. Accessed December 30, 2005.
15. Grossberg GT, Desai AK. Management of Alzheimer's disease. *J Gerontol Med Sci*. 2003;8A(4):331-353.
16. Beck CK, Vogelpohl TS. Cognitive impairment and autonomy. In: Gamroth LM, Semradeh J, Toinquist EM, eds. *Enhancing Autonomy in Long Term Care*. New York, NY: Springer Publishing Co; 1995:44-57.
17. Rosto L. Patient first: when caring for patients with dementia, person-centered care is best practice. *Advance online editions for OTs*. Available at: <http://www.advanceforot.com>. Accessed September 20, 2003.
18. Wagner L. Focus on caregiving. A scientific profile for dementia care. *Provider*. 2000;24-25.
19. Allen CK, Earhart CA, Blue T. *Occupational Therapy Treatment Goals for the Physically and Cognitively Disabled*. Bethesda, Md: American Occupational Therapy Association; 1992.
20. Reisberg B, Franssen E, Bobinski M, et al. Overview of methodologic issues for pharmacologic trials in mild, moderate, and severe Alzheimer's disease. *Int Psychogeriatr*. 1996;8:159-193.
21. *Reference: The Merck Manual of Diagnosis and Therapy*. Section 21. Special Subjects Chapter 291. Available at: [www.merck.com](http://www.merck.com). Rehabilitation Accessed online January 2, 2005.
22. Mendez MF, Cummings JL. *Dementia: A Clinical Approach*. Philadelphia, Pa: The Curtis Center; 2003.