MENTAL WELLNESS IN AGING

STRENGTHS-BASED APPROACHES

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CARING FOR PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

Strengths-Based Approaches

Judah L. Ronch

AS A GROWING NUMBER OF PEOPLE with Alzheimer's disease (AD) and related dementias enter the United States health care system, particularly the long-term care health care system, interest among professionals has moved away from the medical model of care toward *person-centered* care. Primary caregivers—family and paid staff—are learning to improvise a path of care while cures to AD and related dementias are sought because the system's previous exclusive reliance on the acute care medical model is not proving effective.

As innovation and improvisation took hold among care providers and produced informal consensus and communities of practice, a sense emerged that despite the relentless progression of AD, staff and caregivers were indeed able to help the person with AD by using "whatever [their] ingenuity and hearts suggest"

I wish to thank Drs. Eron and Lund for their discussions over these many years that allowed me to use their constructs and theory in refining my earlier work on the experience of the "self" in AD. I am in debt to Jean Marks for her always astute and expert comments, for her editing of earlier versions of this manuscript, and for help with the references. She often understood the essence of what I wanted to say and helped me clarify the message. Despite this expert help, I am solely responsible for any errors in this chapter.

(Luria, 1985). The literature and professional conferences continued to showcase "best practices" and creative programs that grew from intuitive hunches, adaptations of interventions successful with other populations (e.g., individuals with developmental disabilities), and other ground-breaking thinking. Best practices and creative programs developed, usually by nursing home and day center paid caregivers, who believed that there had to be a better way to give care than by responding to "problem behaviors" when they occurred. Ultimately, the ways of the paid caregiver joined with the innovations thought up by family caregivers.

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Family caregivers improvised and became creative on their own to meet the multiple, cascading needs of relatives for whom they cared; they shared their newfound solutions in support groups and Alzheimer's Association newsletters. Because there were few acceptable alternatives, however, people with AD, along with the family members they cared about, were held hostage by a hateful disease characterized by one caregiver as "a maniac" (Roach, 1985). Through support groups and professional channels, an inventory of innovative approaches began to evolve out of family caregivers' and paid caregivers' trial-and-error experiences. A caregiving *wisdom* arose and became popular among paid and family caregivers because it provided a valuable tool kit of practical, commonsense approaches that were more effective than anything modern medicine offered at that time.

The effectiveness of these improvised innovations was difficult to study under strict controlled conditions because controlled studies are confounded by definitional, ethical, and measurement problems (Holmes, Ory, & Teresi, 1994). Uniformity was lacking in treatment approaches, making direct comparisons elusive. This lack of empirical, behavioral research initially led to the use of studies of outcome measurement in which stories of the person with the disease were not subordinated to statistical analysis. This led to a greater breadth of understanding among all caregivers about how the people with the disease responded to various interventions and care practices. To achieve a fuller appreciation of the path to person-centered dementia care and to highlight the positive developments in care for people with AD on which to build future care paradigms, it is important to look at the historical milestones leading up to the current approaches in dementia care.

HISTORICAL PERSPECTIVE OF STRENGTHS-BASED CARE AND ALZHEIMER'S DISEASE

When helping an individual contend with AD, using the person's residual strengths is now the norm because of important changes that have taken place in how society views people with AD and how people with AD view themselves.

This shift toward "person-centered care" (Kitwood, 1997) has resulted in a new way of looking at and talking about AD and its effects that goes beyond thinking of AD as being only a neurological condition.

The impetus for a new care model to help individuals with AD and provide support for care providers arose out of a fortunate confluence of scientific, demographic, and sociopolitical changes during the 20th century. Shaped by advances in how scientific phenomena and people's behavior were understood, these innovative models were the lens though which the behaviors of people with AD were given new meaning. The productive interweaving of scientific advances and optimistic views of what human beings are capable of doing to help themselves continued to evolve and gather momentum at the dawn of the 21st century. With the clarity of hindsight, eight milestones may be identified that combined to generate and energize this movement:

1. Dr. Alois Alzheimer's pioneering work
2. Research that debunked the myth of senility and established the biological, psychological, and social bases of cognitive impairment in aging adults
3. The practice of educating family caregivers about AD and making them the focus of professional intervention, even while the idea persisted that there was nothing that could be done for the person with the disease
4. Patients' rights movement
5. Dynamic view of behavior of AD patients
6. Establishment and growth of the Alzheimer's Association and its affiliated branches around the world
7. Medicines approved for treating AD
8. Strengths-based models of mental health interventions

Each milestone had a pivotal effect on a care paradigm—and the whole had a greater impact than the sum of the parts in promoting person-centered care for people with AD.

The Work of Dr. Alois Alzheimer

Amid the promise of an ultimate cure generated by the biomedical research on AD being conducted as this book was being published, it may be easy to forget Frau Auguste D., the first person to be diagnosed with an Alzheimer's-like condition that now bears Dr. Alzheimer's name. Fifty-one-year-old Frau Auguste D. had been wandering the city of Frankfurt, Germany, screaming in the streets, and causing her socially prominent husband and her family great embarrassment. She accused her husband of infidelity and her doctors of rape (Pierce, 2000).

Dr. Alzheimer believed her to be suffering from "presenile dementia," a condition known for many centuries and believed to be associated with atrophy of the brain. After she died, Alzheimer performed an analysis of tissue taken from Frau Auguste's brain. He found that she had a profusion of thickened neourofibrils, or *tangles,* arranged in bundles within the cells and neuritic plaques in the intra-cellular spaces. These remain the unique pathological signs of the disease. Alzheimer's classic papers, published in 1906 and 1907, proposed that Frau Auguste D. had not been a victim of presenile dementia (presumably vascular in origin) as he had first thought, but rather that she had been a victim of a specific, unique neurodegenerative condition now called Alzheimer's disease.

Dementia senilis, senility (a term that is now considered anachronistic), was a common diagnosis for older adults whose behaviors included wandering and acting suspicious, confused, and verbally disruptive. Though its clinical presentation was remarkably similar to Frau Auguste D.'s, dementia senilis was believed to be the result of reduced cerebral blood flow secondary to normal arterial narrowing or hardening of the arteries as people aged. No one thought at that time, or for many years thereafter, that Frau Auguste D. and the many older adults who were considered senile could be suffering from the same disease.

DEBUNKING THE MYTH OF SENILITY

Based on the groundbreaking work of doctors Blessed, Tomlinson, and Roth (1968) in England, and the research of Katzman (1976), Terry, (1963), and their colleagues (Katzman & Karasu, 1975; Katzman, Terry, & Bick, 1978) in the United States, researchers were able to demonstrate that older people who became forgetful, lost their social and language skills, and had diminishing related cognitive functioning were not suffering from inevitable senility but had specific neural damage in their brains that was visible under the microscope during autopsy. They found that in the majority of individuals with these symptoms who were examined, the neural damage was the same type (i.e., neuritic plaques and tangles) described by Alzheimer in his studies of brain tissue from Frau Auguste D. and other patients with similar clinical pictures who died before age 65. Furthermore, the majority of older people who had no equivalent behavior difficulties (i.e., were not forgetful or functionally limited by memory impairment) did not manifest the same profusion of plaques and tangles in their brains as did those with cognitive, functional, and behavioral problems. The realization that a majority of older people who experienced cognitive impairment were suffering from the same disease as Frau Auguste D. (or some other identifiable organic pathology) was a significant breakthrough in how scientists and practitioners began to view cognitive impairment and dementia (i.e., as a result of illnesses, not merely normal aging) (see Torack, 1983, for a thorough review).

ALZHEIMER'S: THE FAMILY DISEASE

Clinicians traditionally were taught to diagnose the patient's condition and to treat the family of the person with AD. This approach reflected sensitivity to the family's stresses and caregiving burdens but excluded any direct intervention with the person with AD. The family's experience was the focus of the therapeutic intervention; the lack of specific medical intervention to treat the disease itself had made the effect of the dementia on the patient a secondary clinical consideration. Inevitably, sympathetic conversations with the family took place, mostly about placing the person with AD in a long-term care facility (typically in a psychiatric facility or nursing home). Such discussions—and the family's reactions likely based on feelings of guilt and shame—took place without the person with AD being present, or worse, if he or she was present, they were conducted as if the individual was not there.

With the initial breakthroughs in research and practice, Nancy Mace and Peter Rabins, M.D., in their classic book *The Thirty-Six Hour Day* (1981), were able to comfort and empower with knowledge those families caring for individuals with AD. Most important, Mace and Rabins provided families with something they seemed to want most desperately—a way to be caring as well as the primary caregiver (i.e., to keep the AD relative home with the family). Mace and Rabins taught the family about the nature of AD, the underlying bases of the behavioral changes they witnessed, how to be helpful to the patient and other family members when extraordinary behaviors occurred, how to prevent extraordinary behaviors, and how to understand the impact of the disease's manifestations on the emotional and social life of the whole family.

During this same period, public psychiatric facilities downsized and/or focused on patients who were younger and acutely ill, and nursing homes became reluctant to admit people with challenging behavior or AD if there were other, less–problem-prone candidates awaiting admission. Families had limited choices of satisfactory institutional alternatives, and assisted living, day care, and trained home care aides were not available.

The phenomenal response to *The Thirty-Six Hour Day* (now in its fourth edition) demonstrated that family members desperately needed and would embrace a compendium of tools and wisdom that helped many of them follow their preferred way of caring for a person with AD at home for as long as possible. *The Thirty-Six Hour Day* was also one of the first available resources that professional caregivers, especially those in nursing homes, could turn to for in-depth, psychosocially based explanations of the problematic behaviors (e.g., wandering, aggressiveness) that were typical of residents with AD. Mace and Rabins' book explained problem behaviors using motivational models that went beyond the strictly biological explanations of behaviors that were the standard of the time. By demonstrating the differences in behaviors, Mace and Rabins provided caregivers with strategies to prevent these behaviors from occurring by understanding each resident's emotional status and response to the demands of the environment. These insights helped nursing home staff develop special programs and interventions for residents with AD that engaged the residents' interests and reframed their problem behaviors as signs of poor person–environment fit, thus encouraging care providers to modify the environment as the most direct way to reduce the problem behaviors.

PATIENTS' RIGHTS MOVEMENT

The rise of the patients' rights movement in the United States changed the way society viewed people with chronic physical or mental illnesses and the way people with AD viewed themselves. The reports that patients with cancer, heart disease, and other illnesses who became active participants in their treatment had better survival rates and significant increases in longevity (Cousins, 1974, 1989) suggested that patients who were actively engaged in combating their illness did better than those who passively received treatment from others. Recent research findings (Salovey, Rothman, Detweiler, & Steward, 2000; Taylor, Kemeny, Reed, Bower, & Greenwald, 2000) increasingly supported the value of an active model of engaging the disease as a significant and concrete way for people to escape the additional problems arising from the passive experience of their illness. This active model entailed individuals becoming empowered and doing something positive by participating in their care. The presence of a disease does not negate or disallow the patient's intact abilities from being factors the patient can mobilize to contribute to his or her recovery.

As people with physical disabilities had asserted the primacy of who they were as people, those with cognitive disabilities began to speak out on their own behalf and increase society's awareness of the talents, strengths, aptitudes, and the capabilities they had that they could put to use alongside professional intervention to promote their own well-being.

The patients' rights movement illustrated the possibility of reframing society's view of a clinical population previously characterized primarily by diagnoses and disabilities. The movement helped practitioners to focus their care toward enhancing an individual's capabilities without, for example, unearthing the ontogenetic roots of all mental health problems or requiring a cure for all the patient's problems. In other words, for the person who had a physical or mental illness, the patients right's movement portrayed the message, "Just because part of me is not in optimal condition, all of me isn't sick," as well as the message, "We are able to be help ourselves by using what is strong to fix what is wrong." Society had consigned people with disabilities to the wrong side of the "hypermobile" and "hypercoping" worlds of the "well" against their will, much as society presumed that people with AD had left the "hypercognitive world of the intellectually intact" (Post, 1995) once the diagnosis was made.

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Society's view of what it means to have an illness had changed. An illness could no longer only be seen as something that defined a person (e.g., hemophiliac, schizophrenic). Having a diagnosis did not make him or her fundamentally different from his or her contemporaries. An alternate view had emerged that proposed that an illness was not something that redefined an individual if he or she did not allow it. The patient's constellation of attributes, strengths, and other coping mechanisms that predated the illness were not forfeited when a serious mental or physical illness occurred. Just as people in society without an illness are expected to be independent and strong on their own behalf (and in whom passivity would be frowned on), this view advocated that people with an illness could be expected to use whatever abilities they had at their disposal to promote a better quality of life while, and possibly after, being ill.

The change from seeing the individual as a passive victim to seeing the individual as being an active participant in the experience of the illness allowed his or her feelings about being ill to occupy a central and even decisive role in informing care and treatment choices. The individual's feelings about the illness, degree of resilience, coping style, available strengths (e.g., humor, faith, tenacity, survival skills, self-control) came to be seen as assets that the patient brought to a new role as a teammate of health professionals, relatives, friends, and other caregivers. One later and very creative manifestation of this development was the rise of therapy groups and organized advocacy activities that involve people in the early stages of AD (see Chapter 15 for examples).

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Although a total cure or increased survival rate was not always achieved for all illnesses, new ways of helping people cope with illnesses were emerging. These collaborative strategies and the positive impact they had on people's health allowed the person who was ill to be viewed as the source of unique and critical information—the effect that their experience of the illness had on their symptoms, goals, prognosis, and outcome.

BEHAVIOR AND THE INDIVIDUAL WITH ALZHEIMER'S DISEASE

Dr. Alvin Goldfarb—a gifted clinician, dedicated teacher, and one of the pioneers of geriatric psychiatry—reminded clinicians that the dynamic unconscious, first described by Freud, did not cease to play its usual role in determining a person's behavior after the onset of a dementing disorder (Goldfarb, 1961, 1969, 1974). Goldfarb predated the patients' rights movement by many years. By analyzing the behavior of older people and those with AD through the lens of Freud's dynamic psychiatry, he advised clinicians to look for the evidence of normal psychological processes and their use of available defenses against anxiety when considering each patient's attempts or behaviors—successful or not—to adapt to his or her unique experience, including memory loss. He explained that the disturbed behavior of someone with AD was understandable if the basic tenets of dynamic psychiatry were applied (i.e., that behavior remains motivated by unconscious defenses against anxiety and is not random, accidental, or wholly a result of the disease). By reminding clinicians of the influence of the normal intrapsychic mechanisms in each patient with neurological disease, Goldfarb told them that *Alzheimer's disease* was not the generic answer to all questions about why people with AD behaved as they did. Goldfarb's analysis contained the understanding that the disease *had* the person, and not vice versa.

A related perspective on neurological diseases gained a wider audience through the popular writings of Dr. Oliver Sacks (1985). His many books have personalized a variety of diseases by virtue of his gifted ability to tell the stories of an assortment of people with neurological maladies that do not lose the person *in* the illness. He, too, has encouraged clinicians to attend to the experience of the person with the illness when deciding on treatment strategies, including the gifts, quirks, and all the rest that makes that person human.

THE ALZHEIMER'S ASSOCIATION

The creation and growth of the Alzheimer's Association (see Fox, 1989) and, in particular, its network of affiliated local chapters brought the voices of the people with AD, their families, and friends to the center of public, political, and scientific discourses about AD. As a strong advocacy, educational, and consciousness-raising organization, the Association brought AD out of the shadows and reduced the feelings of shame and isolation felt by so many people with AD and their relatives. The Association has raised public awareness about the disease's devastating impact through public events, caregiver training, and support activities and has sponsored scientific research to find a cure; and public profile of the disease continues to grow as family members of celebrities and well-known individuals are affected by AD. The overall impact of the Alzheimer's Association is probably best appreciated in the way that the public recognizes AD as a disease and the fact that people with AD are not as likely to be written off as senile.

MEDICATIONS FOR AD

Although there is no cure for AD, available medicines demonstrate the ability to slow down the relentless progression of cognitive and functional deterioration in some individuals who are in early and middle phases of the disease. The drugs, and those under development, may help to forestall the financial and psychological cost of institutional placement for some people with AD. In essence, medicines may offer a way to slow down the clock so that families may have a longer period of time during which they may experience and enjoy the intact cognitive functions of the person with AD. The positive effects of these medications is not lost on people with the disease, who have responded with evident relief and pleasure to their therapeutic effects. Although very new to the market and far from what is really needed to turn the disease around, these drugs offer a chance to forestall (but not halt) the effects of the disease as medical science zeros in on better therapies.

STRENGTHS-BASED PSYCHOTHERAPIES

The development of modern, strengths-based psychotherapeutic approaches, such as those found in this volume, have added a pivotal dimension to AD care. These approaches utilize the strengths of the individual to achieve change without first having to impose a pathologizing frame to establish the agenda of therapy. Thus, they don't require the unequal relationship in which the view of the professional dominates when conceptualizing the problem and its possible solutions. In this sense, strengths-based approaches create the basis of "I–Thou" (Buber, 1970) relationships in which each party is an equal of the other and personhood is preserved in both, even if formal psychotherapy is not used as an intervention. In AD, the strengths-based approach (Cohen, Kennedy, & Eisdorfer, 1984) may be combined with an understanding of the perspective of the person with the illness (Cotrell & Schulz, 1993; Ronch, 1996) to establish a collaborative, nonimposing relationship to deal with AD in an active way.

STRENGTHS-BASED APPROACHES AND PROBLEM BEHAVIOR IN AD One advantage of the strengths-based approach to helping people with AD is that it opens up myriad opportunities to intervene in a psychosocial domain, in which traditional therapies, especially pharmacotherapy, have been less than dramatic in their impact (Cohen, 1997; Maletta, 1992). Although new medications target the neurochemical mechanisms implicated in AD, they have been less successful than "low tech–high touch," interpersonal approaches in altering the impact of dementia on the person's psychosocial functioning in a significant way (Cohen, 1997).

Cognitive-behavioral intervention (Teri & Gallagher-Thompson, 1991), person-centered care cultures (Kitwood, 1997), environmental refitting and normalization (Fagan, Williams, & Burger, 1997), and individualized music selections (Gerdner, 2000) all have been reported to have had a positive impact on the supposedly unmodifiable difficult behaviors assumed to be intrinsic to the disease and primarily caused by associated brain damage. These findings support a paradigm shift from *illness-centered* to person-centered views of behavioral phenomena in AD. As a result, a door is open for clinicians to recast the stereotypes regarding the possible psychosocial origins and treatment of the behavioral symptoms of AD.

The ultimate goal of person-centered care is to improve the quality of life of the person with AD and the lives of those people who care for them in paid and unpaid capacities. Shifting from an illness-centered, biomedical model of disease to a person-centered, biopsychosocial model permits caregivers to go from passive observers of chronicity (Kleinman, 1988) to active caregivers in maintaining an individual's sense of self. This change of view has two interrelated benefits. First, it allows the caregiver to engage the person rather than the illness when trying to bring relief, thus targeting what is potentially alterable (i.e., the behavioral repertoire of the person, rather than the immutable illness). In this approach, a hopeful mindset is created and chronic helplessness and caregiver burnout are avoided; helplessness and burnout being the inevitable consequences of seeing the disease as only responsive (modestly at best) to medication. Second, people with AD are challenged to engage their own coping strengths in a context of optimism about the results, rather than in an atmosphere of despair and inevitable failure. In Kitwood's (1997) terms, a "malignant social psychology" is replaced with an enabling one that supports personhood and all of the positive behavioral potential that such an approach may evoke. The operative interpersonal dynamic is one of collaborative problem solving as opposed to custodial control.

Kitwood's concept of a positive social psychology promotes care of people with AD based on an ecological, adaptational viewpoint of their behavior. It asks the questions: Why did a particular behavior occur *now?* To which aspects of the internal or external environment is an individual responding? And how is he or she experiencing the world and giving meaning to events based on remaining memory for information and of his or her self? This kind of psychosocial model of motivation posits that an individual's behavior results from trying to fulfill unmet needs (Cohen-Mansfield, 2000) or arises because of excess environmental stress that cannot be ameliorated by previously adaptive responses. The model presumes that all behavior of people with AD does not result only from the direct, organic impact of dementia (Cohen-Mansfield, 2000; Lawler, 1995). Because problem behaviors in people with AD are often caused by multiple factors, a complete assessment of possible physiological (e.g., physical illness, medication [Feinberg, 2000]), environmental (e.g., noise, isolation), and other potential bases of the behavior is essential before a psychosocial approach is warranted as the sole intervention (see Cohen-Mansfield, 2000).

If the person with AD is indeed trying to adapt in order to fulfill unmet needs or is responding to environmental stressors, it would be plausible to believe that he or she would rely on available memory, which, in AD and similar disorders, would be composed largely of what is stored and available in remote memory. The person with AD would logically rely less and less over time on his or her recent memory. This approach to understanding behaviors observed in people with AD allows clinicians and caregivers to look at the person's behavioral repertoire, and especially so-called difficult or problem behavior, as evidence of the person's attempts to cope and adapt successfully. The problem results from a person's failure to engage the appropriate behavior in the present situation because of diminished cognition and a dwindling reserve of memory traces associated with successful solutions to the current problem (a poor fit between context and retrieved memory), not from a desire to create a problem.

This analysis is at odds with the typical interpretation of problem events reflected in the behavioral lens of traditional terms used to categorize them, such as *acting out, infantile, regressive,* or *disruptive.* Terms such as these carry implicit messages of malevolent intent or psychopathological origins of the behavior and create a mindset in caregivers that orients them toward protecting themselves or controlling the behavior by force to prevent an impending catastrophe. Unfortunately, responses tied to these interpretations usually bring about precisely those awful consequences caregivers were hoping to prevent.

The dominating frame of reference in dementia care used to categorize and cope with problem behaviors preserves the viewpoint of the caregiver when attempting to explain and intervene. As long as the behavioral repertoire of the person with AD is seen through the lens of an implicit cultural bias embedded in contemporary caregiving (i.e., that the motivation of the patient's behavior is viewed from the point of view of the caregiver), the behavior will be seen and responded to as problem *creating* rather than problem *solving* in origin. The older adult's behavior and intent are judged on the basis of their impact on the caregiver, not from the viewpoint of the older adult attempting to cope with his or her daily life that has been co-opted by a disease and his or her reaction to it. It is a decidedly unempathetic and defensive view, aggravated by misattribution and misunderstanding about what happens to the person with the disease and where the purpose of behavior originates (Feinberg, 2001).

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PERSON-CENTERED CARE AND THE ROLE OF THE SELF IN THE EXPERIENCE OF THE DISEASE

Approaches to dementia care at the dawning of the 21st century have a postmodernist spirit because the approaches perceive that the biological condition as well as the person's experience with it make up the field for intervention (Morris, 2000). This view is similar to a line of thinking that advocated more humanized care (see Bowker, 1982) that could be achieved by changing the focus of care to the individual with the illness and away from the modernist scientific practice of caring for a class of people through a uniform set of care tasks. The evolving, postmodernist view benefits patients and care providers when the patient, not the dementia, is cared for in an atmosphere rooted in collaborative, interpersonal relationships because illness is "a social state of affairs" (Gadamer, 1993) that involves people, social institutions, cultural practices, and shared meanings (Morris, 2000).

The central and inescapable role of an individual in a caring relationship with someone with AD was addressed in Cohen and Eisdorfer's (1986) characterization of AD as the "loss of self." Molly, a patient of mine, first articulated the essence of this phrase many years ago during our initial interview. She explained her tendency to rummage through closets and drawers of other residents in her nursing facility as an attempt to find herself. At this time she could no longer do things (e.g., read and remember what she'd read) that defined for herself who "the real me, the real Molly was" (Ronch, 1987).

Molly's definition of her experience with AD and how it was a "self-altering" phenomenon, was echoed in Oliver Sacks's classic stories about the vicissitudes of people's lives as they are affected by neurological illness. He observed that "a disease is never a mere loss or excess—there is always a reaction of the affected organism or individual to restore, to replace, to compensate for, and to preserve its identity, however strange the means might be" (Sacks, 1985, p. 4). Feinberg's work (2001) on how brain damage inevitably affects the patient's experience of self, like Sacks's observation, is an important dictum for practitioners to remember while they contemplate the social state of affairs of people with AD. They must incorporate this concept when creating a theory of why a particular behavior has occurred.

Damasio (1994, 1999) and Feinberg (2001) both proposed that an individual's *self*, the core target and potential participant in the collaborative, person-centered care relationship, has an identifiable neurological substrate but no single neuroanatomical locus (site). Though a fuller explanation of their intriguing ideas is beyond the scope of this chapter, their attempts to locate the neurological mechanisms at the root of an individual's self in the structure and function of the brain permits use of the term *self* as more than a vague theoretical construct. It suggests a physical basis for the essence of an individual's experience of AD and a target of therapeutic impact.

Damasio described the neural basis of the self as being built on a continuously growing body of autobiographical data; that is, the self is a "perpetually created neurobiological state" (1994, p. 99). This conceptualization helped to build a self-based, problem-solving view of what happens in people with AD when problem behaviors occur. "In brief," he wrote, "the endless reactivation of updated images about our identity (a combination of the past and of the planned future) constitutes a sizable part of the sense of self as I understand it" (Damasio, 1994, p. 239). People with AD increasingly rely on images from the past that are contained in the remote memory of self and are increasingly unable to plan a future. Thus, it would appear that the portions of autobiographical memory they use to make sense of current events, to recall, as everyone does, "interpretations of past events" (Damasio, 1994) in the context of the present, and to maintain identity in the process increasingly would reflect knowledge of the self from the past. This was, as Molly described in our interview, the goal of her rummaging behavior. The self is not composed of objective or photographic memories of events, says Damasio (1994), but rather is the product of a subjective and creative process of selecting and interpreting personal experiences into an ongoing sense of self (Scheibe, 1989). Attempts at problem solving such as Molly's will make use of responses that are likely to fit with her remaining knowledge of her self, even as her memory of specific events and the ability to recall them vanish. Possible solutions are retrieved because of having been confirmed *in the past* as successful solutions in situations that have sufficient similarity to her current problem. Thus, for Molly and other individuals with AD, meaning is largely determined by the self as embedded in memories of the past that appear to fit the present contextual demands. But, sadly, these old memories of self increasingly do not fit the present.

Feinberg made use of contemporary neurological data to conclude that the self is "the subject of our conscious experience and at the core of our being":

> Many different areas of the brain contribute to the preservation of the self, but there is no "material locus of the self" or inner "I" within the brain. The brain

> creates the self by producing a nested hierarchy of meaning and purpose, where the levels of the self, and the many parts of the brain that contribute to the self, are nested within all other levels of the hierarchy. (2001, p. 149)

We experience ourselves as unified, he concluded, "because our meanings and our actions are unified within the nested self" (p. 149). That suggests that the person with AD engages in the act of maintaining the unified self as the disease progresses and would presumably continue to do so until the areas of the brain necessary to process meaning and purpose are gone. This is what Molly expressed to me, only more simply. Behavior, such as her rummaging, can therefore be viewed as her attempt to maintain her *unified self* in the face of missing some vital personal information she needs to do so successfully.

Feinberg's position that *purpose* exists "only from the inside perspective of the self" suggested that the knowledge of why people with AD do something cannot be located in the brain or known by identifying where the brain is damaged. "The ontology of purpose and action, like meaning, is irreducibly personal" (2001, p. 148). The self is not a *static entity,* according to Damasio (1994) and Feinberg (2001), so it would follow that the self undergoes changes as dementia is experienced. The "margins of the self" are always being transformed, wrote Feinberg, claiming that this process occurs in all of us, whether or not we have brain damage.

These observations allow those who work with people who have AD to put problem behavior into a completely different context and analytical frame, and the behavior of people with AD can now be viewed from a strengths-based perspective. Their behavior may now be interpreted as motivated to preserve their *unified self.* Eron and Lund (1996; see Chapter 12) observed that people have strong preferences with regard to how they would like to behave, to see themselves, and to be seen by others. They referred to this constellation of ideas about self as a person's *preferred view.* These are the ideas about the person's behavioral preferences that best fit how they see themselves and, thus, provide the basis or motivation for preferred explanations about why a person does something. A person's behavior, and how others respond to it, may confirm or contradict his or her preferred view. For example, a person with AD might explain his or her behavior to his or her self and/or others by making reference to the diagnosis: "I lose my way at times because I have AD. Can you tell me where the men's room is?" He or she might explain his behavior by attributing it to some other cause: "I can't find my money; why did you hide it?" The essential point is that having AD might or might not fit a person's preferred view at any time, and is less likely to fit it as the dementia progresses and the images of an individual's self in old or remote memory storage lacks any knowledge of having AD. This lack of knowledge is not denial in the classic sense but rather amnesia for an aspect of autobiography and a missing piece of the self as it is presently known.

When a practitioner attempts to help an individual with memory impairment using interventions predicated on demands that the individual acknowledges his or her memory impairment (i.e., as by accepting the "fact" that they are "forgetful"), the practitioner runs the risk of confronting the individual with input that doesn't fit his or her preferred view. The individual with AD has little or no memory of that aspect of the self he or she currently knows. At times like this, the person with AD is faced with his or her own perceptions that are in conflict with those of helpers who clash with his or her preferred view and is pressured to believe the "truth" of his or her forgetfulness. Though trying to be helpful, the practitioner is actually imposing an aspect of the patient's self that is largely or entirely unknown at that time. The experience can create a gap or *disjunction* that fuels problem cycles, creating negative and unsettling emotions.

Interactions like these that are based on the medical model approach to AD deny the validity of the individual's experience of the illness and introduce an additional burden. That is, the person with AD will experience a negative emotional state (e.g., frustration, sadness, anxiety, dysphoria, resistance, oppositional behavior, anger) and more behavioral difficulties as the gap between his or her preferred view ("I do remember") and the disjunctive view of the caregiver ("You have a memory problem") widens (Eron & Lund, 1996).

STRENGTHS-BASED CARE IS PERSON-CENTERED

Recognizing that people with AD retain adaptive capacities, it is possible to examine how strengths-based care embodies a person-centered approach and how these ideas may be put into practice. One advantage of this particular view of people with AD, and, therefore, of the culture of care best suited to enhancing quality of life, is that relationships with them can now include them as active participants up to the limits imposed by the disease. Their role is no longer subject to the limits imposed by therapeutic treatment models. For example, it has been found that when the person with AD is expected to be passive, as is typical of some traditional care practices, bathing people with AD creates more work for staff and excess disability (reduced optimal level of function created by care practices or medical intervention with the patients). When increased independence is introduced and encouraged, the excess disability may be reversed and people with AD become more autonomous (Rogers et al., 2000).

In essence, person-centered care (Kitwood, 1997) sees the behavior of people with AD as a reflection of the experience of the illness and as a manifestation of the narrative or story of the illness in their lives (Morris, 2000). Commenting on Frank's (1996) *The Wounded Storyteller,* Morris wrote about the essence of what practitioners might consider the essential process of mutual personal change in the caregiving relationship that defines the process of becoming (continual evolution of the self). "Telling the stories of their illness," Morris explained, "constitutes a moral action by which the ill negotiate the reshaping of their own lives. Listening to such stories and responding to them with empathy constitutes for the listener an equally important moral act that also contains a possibility for significant life changes" (Morris, 2000, p. 257). It is largely through their behavior that people with AD tell their stories. By observing, listening, and responding with empathy rather than with judgment and avoiding the temptation of "translating them into biomedical dialects" (Morris, 2000, p. 258), the caregiver avoids becoming merely an attendant to deterioration (Kleinman, 1988). The caregiver is able to be a healer by being a witness, not a judge, as the "margins of the self" (Feinberg, 2001) in both participants transform.

The person-centered approach rewards caregivers with more opportunities to engage their own personal strengths and chances to bring out and support the strengths of people with AD. As Kitwood (1997) observed, caregivers can connect with a person with AD by bringing their own emotions and empathy to the caring relationship. As caregivers do this and depart from the emotional detachment and scientific objectivity demanded by the medical model, they make restitution for the emotional impact of loss of self, a gradually occurring process, which is at the heart of developing dementia. This model addresses the problems of caregiver demoralization and burnout by validating and celebrating the mutual emotional exchange that typically happens in human relationships of any value. Due to the collaborative nature of the psychosocial model, both the practitioner's and the patient's feelings are involved in and enhanced by the process.

DESTROYING THE MYTH

The myth that the person with AD has passed into an existence that is fundamentally different once the diagnosis of AD (Post, 1995) has been made is an additional barrier to person-centered, strengths-based care. This belief encourages practitioners to treat everyone with the same diagnosis as if by applying an unalterable formula, a stance that results in a closed-loop dynamic in which treatment and explanation are mutually reinforcing and self-perpetuating. Post (1995) wrote of the passage out of the "hypercognitive world" of the cognitively intact once a person is diagnosed, in which the explanations of human behavior and the validity of personal choices no longer apply to the person with AD—regardless of the actual nature or severity of an individual's cognitive loss. Though alternate models for understanding the behaviors of a person with AD have received empirical support (Cohen-Mansfield, 2000), biomedical frames still predominate in most approaches to explain the behavioral difficulties in people with AD (Lyman, 1989).

The following pages contain examples that illustrate the person-centered, strengths-based approach. The first vignette reveals how this approach helped a woman with AD and her family to resolve an issue of problem behavior by looking at the experience of the woman with dementia as expressed in her behavior. This demonstrates the role of collaboration in arriving at a solution and how the practitioner can discover information by understanding the experiences of the person with AD and his or her family members. Because the person-centered approach enlists the strengths of an individual, this case's intervention demonstrates how the practitioner builds on the individual's past and successful attempts to solve similar problems in order to learn about the preferred view currently held by the person with AD.

Mary

Mary, age 76, was brought to my office by her very distraught daughter Helen and Helen's husband John. They all appeared angry, frustrated, and ready to explode—though they all tried to be in control and objective about why they had come to see me. As I welcomed them, John presented me with a small package of papers. He told me that the papers were documents for me to sign to attest that Mary was forgetful and lacked the capacity to make a competent decision; the one at issue being to return to her own home that very afternoon. John and Helen had informed Mary that she was unable to take care of herself, and that if she chose to do so, they were not legally liable for the outcome. They believed that Mary was suspicious of them, and she resisted any advice they gave to her about the inadvisability of her return home at this time.

After I recovered from the surprise I experienced on being confronted by this demand, I gently informed the family that I was not prepared to sign any papers attesting to anything about Mary's mental or functional status, nor would I be at any point that day. I further informed John that if it was a legal opinion he wanted or if he wished to avoid legal penalties for the outcome of Mary's decision, he had come to the wrong place. I did ask to see the papers and found that they were a detailed presentation of what had happened with Mary and how she had refused to go along with the family's attempts to ensure her safety. I then asked them to come into my office so we could all talk about the problem.

Helen told me that her mother, Mary, who was a retired nurse, came to live with her and John to continue her recovery from a recent fall and broken forearm, which had resulted in a 2-week hospital stay in Mary's home town 50 miles away. Mary had been found to be forgetful and mildly malnourished on her admission to the hospital and had lost 10 pounds. After her accident, Mary regained sufficient functional ability to dress herself with assistance and to eat—but not to prepare her own meals. But, Helen and her family members worried about Mary's forgetfulness and felt that she couldn't take care of herself even when her arm was fully healed.

Mary smiled and immediately said that her daughter and son-in-law were very caring but overly concerned and that her memory was quite good for someone her age. When I asked her whether she remembered why she had been admitted to the hospital, Mary correctly responded that she had fallen after "passing out, I guess." Helen interjected that Mary's next-door neighbor, who had called the police for help, had found Mary unconscious. Mary said that while she had not been well, she now felt ready to go home and wished to "stop imposing on the children's hospitality." "They have been wonderful to me and that's why I'm in such good shape," she volunteered, "but it's time for me to go home today and get out of their way."

John then added that Mary had spent the last 2 days packing her bags and then unpacking them as she and her children went back and forth about Mary's readiness to return home. "And," John continued, "her bags are now sitting in the entry foyer of our house pending the outcome of our visit with you." I then asked about the papers that I was asked to sign and inquired about the intended readers. John said that Helen's brother, who lived in Oklahoma, didn't understand how bad his mother was and that if Mary insisted on going home before she was ready to, they feared they would be held accountable for any possible injuries Mary might cause to herself or to others as a result of her "impaired" mental status. As they left the room at my request so Mary could be interviewed alone, Helen whispered, "And ask her about the drinking."

I had learned that John and Helen were worried about being viewed by others as irresponsible and uncaring—if not legally liable—in the midst of this troublesome and confusing situation. I could now join with them to deal with the crisis that originated in Mary's stated desire to unburden her children now that they had done such a good job in aiding her recovery. The next step involved learning about Mary and her memory problem.

The Interview with Mary I spoke with Mary about her situation and how she felt. When I asked her how her memory was working, she replied, "Fine, I think." I then asked whether she would mind if we tested how good her memory was, especially because people are sometimes unaware of memory problems. She agreed, and the examination revealed that her Mini-Mental Status Examination score (MMSE) (Folstein, Folstein, & McHugh, 1975) was 16 of a possible 30 (moderate memory loss), with particular problems in short-term memory and 5-minute recall items. But what was most interesting was her answer to the question that asked the present year; Mary answered that it was 1942. I inquired about the significance of this date and she said, woefully, that it was when her "baby brother" died in World War II. Her brother's death was a particularly painful loss because their mother had died when Mary was 11 years old and her brother was 3—leaving Mary to raise him. "He was like my own child," she said through tears, "and I miss him like it was yesterday that we got the news that he had died."

After listening to Mary talk about her brother and witnessing her grief, I shared the MMSE findings with her and explained that her type of memory loss was especially difficult to acknowledge and cope with since by its very nature people who had it usually couldn't remember that they had a memory problem. Then, in an attempt to engage an aspect of Mary's preferred view, I asked her whether she had learned about this kind of mental status testing in nursing school. She laughed and answered, "They didn't tell us about anything like that in those days."

Mary's focus on the loss of her brother and the possibility of longstanding, unresolved grief suggested that Mary might have a depressive syndrome (Kennedy, 1995) and, therefore, be sleeping poorly. I asked her if she used any medicines to help with her sleep or to calm her nerves (both insomnia and anxiety are common to older adults with depression and related insomnia). She responded by pulling a huge bottle of an anxiolytic medication out of her purse; it did not have her name on it, in fact, it had no prescription label at all! I asked where she got the medicine, and she replied that her doctor gave it to her while she was in the hospital, to help her sleep. When I expressed doubts that a physician would give a patient a bottle of 500 pills like this, Mary said: "Oh, then maybe I got it from Frances, my next-door neighbor." It was quickly apparent to me that Mary's memory problem was not a simple issue and that the roles played by drug use, poor nutrition, depression, and other causes yet unknown had to be investigated. I proposed to Mary that she meet with me again to investigate these factors as contributing to her memory problem and appealed to her retained professional identity as a nurse, specifying that more assessments were necessary to understand why her memory wasn't functioning optimally. "Well," she said with a smile, "I think that's a good idea but I live too far away to drive back by myself, so I guess I'll have to stay with my daughter until then."

With Mary's permission, I called her primary physician in her presence and informed him about the problem and my assessment of her status, and asked whether the physician was aware of her use of an anxiolytic. He was quite surprised to hear about her use of this drug and he said that he had not prescribed any for her. Because I believed that Mary's mental status might improve if she discontinued using anxiolytics, I arranged for the physician (who agreed with me) to tell her over the telephone to stop taking the pills.

Mary agreed to cease her pill usage when I explained that they might be making her sleep worse. She then cheerily volunteered that she drank a glass of wine most nights to help her sleep when she woke up at 3 A.M. after the pill's effects had worn off. She volunteered: "Maybe I should stop drinking wine at night, too." Mary, who had estimated that this one glass held approximately 6 ounces of wine, announced, "But it's not a problem because it's not like I'm drinking liquor or anything that's not good for you." Mary also agreed to see her primary physician within 2 weeks to receive a thorough physical evaluation.

She informed her family of her decision to stay with them until the next week and her decision to stop using the sleeping pills and wine at night. John and Helen were surprised and slightly confused, but I explained the findings and theorized that Mary's memory problem might be due to or complicated by many factors discovered in the evaluation (depression, alcohol, anxiolytic medication).

The Follow-up Visit Mary, John, and Helen returned the next week and reported that Mary was sleeping better, was less irritable, and was no longer suspicious. They mentioned that her memory was much better but still a problem. A quick re-evaluation showed that Mary's MMSE score had indeed improved by four points, but that her short-term memory was still impaired enough to warrant concern for her safety and necessitated a more in-depth diagnostic assessment.

The most remarkable change was in everyone's affect. Mary was no longer suspicious in front of her daughter and son-in-law and they, too, had become more relaxed and less fearful. They volunteered that Mary was so much better that they were ready to take her back home, and she remarked that they were taking such good care of her that she was not sure that she wanted to leave. We all agreed that Mary needed a complete medical and functional evaluation to see whether she was able to

> live safely alone at home and to take care of all of her needs. It was also agreed that Mary would see a social worker and other mental health professionals to assess her emotional status and that she would have a proper diagnostic work-up for dementia. Finally, Mary agreed to become involved with community agencies that could monitor her overall well-being and to maintain contact with her health care providers and her family about her status. The papers I had been asked to sign the previous week were not mentioned.

The problem-centered paradigm of treatment would have involved a therapist confronting Mary about her lack of memory and her poor judgment. The approach would have attempted to get her to accept the need for subordinating her view of the situation to that of her "rational" family members (i.e., with no memory impairment). It would have required Mary to accept information about her self and her memory status about which she was amnesic. In view of her need to defend herself from John and Helen's insistence that she had memory impairments, I saw their accusations as a likely cause of her defensiveness, suspiciousness, and anxiety in her interactions with her family.

According to Eron and Lund (1996), the presence of these emotions (defensiveness, suspiciousness, and anxiety) indicated that the gap between Mary's preferred view and other people's view of her (i.e., John's and Helen's) was widening and perpetuated problematic emotional states that further reduced her ability to be part of the "realistic" solution. All the talk of her problems made her strengths too difficult to derive and created more entrenched defensive behaviors. It fuelled her insistence that her view of herself was correct and that her children were well-meaning but wrong. Likewise, Mary's daughter and son-in-law were dealing with a widening gap between their need to get along with Mary and at the same time to take care of Mary appropriately, and their belief that others would see them as neglectful or ill-informed if they allowed Mary to go home and she got hurt.

Finally, any attempts by me to impose a solution on Mary that agreed with the family members' view of her dilemma would have indicated that the clinician also saw her as having lost her place in the "hypercognitive" world (Post, 1995) and totally unable to make decisions. Signing the papers provided by John or referring them to an attorney to arrange a capacity evaluation could have served to increased the polarity the family members were experiencing. This could have further threatened Mary's ability to realign her view of her self in the situation while maintaining her preferred view. It could have prevented a formation of alliances among Mary, her family, and myself. By aligning with John and Helen and abandoning Mary, I would have been at risk of widening the gap between Mary's preferred view and others' view of her into a chasm (Eron & Lund, 1996) and exacerbating her symptoms so much that she would be unable to use her remaining ability to collaborate on a solution to this crisis.

When aspects of Mary's preferred view were discerned, it was possible for me to align with her wish to be seen as caring, thoughtful, capable, and open to new information to make decisions. It was also possible to engage her preferred view in how she wanted others to see her. Being seen by others as a well-informed nurse helped Mary to agree to an empirical approach (i.e., "let's see what the data say about your condition before we proceed"), and allowed her to stop acting exclusively on her desire to deny her memory problem and spare her children any further caregiving burden by overstaying her welcome. By aligning with many aspects of her preferred view as revealed in the conversation with Mary, I was able to find a basis for collaborating with her based on the view of her self that remained. We were also able to work on actively realigning the margins of the self (Feinberg, 2001) with her remaining functional capacities and personal preferences.

Wilbur

Wilbur was an 82-year-old resident of a long-term care facility who began a habit of waking up at 2 A.M., getting dressed, and heading toward the main entrance. Staff tried to redirect him and get him to go back to bed, but within 5 minutes he would be headed toward the lobby of the building. He was sent by his interdisciplinary care planning team to see the consulting mental health practitioners in the hope that a sleeping medication would be prescribed or that some other psychotropic drug could be tried for this "agitation" and "wandering." When staff confronted Wilbur, he insisted that it was time to get up; he had things to do. Wilbur's son Frank kept close tabs on his father's status and asked that his father not receive any drugs. He had heard about the possible side effects of the drugs that are used to control behavior in patients who have AD; he didn't want his father to develop more problems. Frank asked whether a staff member could sit with his father when he got up and talk with him, but the facility staff was reluctant to "set a precedent" because "then everyone on his unit would get up and want to have attention paid to them." Staff expressed concern to Frank that his father's "wandering made him an elopement risk" and that they might have to discharge him to a more secure setting if medication failed to solve the problem.

In an attempt to understand what was motivating Wilbur's behavior and to achieve a view of his behavior as strengths-based, the clinician suggested that a nurse's aide ask Wilbur why he was getting up and dressing himself at 2 A.M. Wilbur, a retired superintendant of a large apartment building in New York City, responded that he had to await the coal truck that was due to arrive soon (to re-fuel the coal furnaces). When viewed from Wilbur's perspective, his explanation provided a suggested reframing of the behavior from problem creating to problem solving.

To explore Wilbur's explanation, the nurse's aide on duty during the night was told to accompany him to the lobby and see what happened. Everyone was curious to see what Wilbur would do when no coal truck appeared and especially interested to see how he continued problem solving when his memory of the past didn't produce a solution in the present.

The nurse's aide and Wilbur made their way to the front lobby at 2 A.M. and drank coffee together while Wilbur read the newspaper and awaited the truck. After waiting 30 minutes in which he finished his coffee and scanned the newspaper, Wilbur stood up and announced: "I'm going to bed!" When the curious nurse's aide asked him why, he replied, "Those trucks are never on time, and if they think that I'm waiting up for them, they're crazy." Wilbur's son confirmed that this was a typical occurrence during his father's working life, and that when he would return to bed around 3 A.M., he muttered about the unions that made his life miserable by not delivering coal on time.

This pattern was repeated every night for approximately 6 months. One night, however, when Wilbur awoke and was asked by the night nurse if he was going to await the coal truck, he said he wasn't going to wait for it in the lobby that night. "If they want me they can find me," he proclaimed as he went back to his room, without cueing, and went to sleep.

Staff viewed Wilbur as a *problem creator* because their modernist, scientific explanation of his actions didn't allow for any alternate view of his behavior. For them, Wilbur's actions were seen from the perspective of how his behavior negatively influenced them and their well-being. Their fear of liability if he wandered out or their belief that they would be overwhelmed with requests to give all residents individual attention determined their view. The need for staff members to preserve their preferred view of being competent professionals supported their need to protect themselves because they believed there was nothing they could do except restrain or medicate Wilbur. Allowing him to get up and move about, possibly fall, or escape the facility would conflict with the staff's preferred view and widen the gap between how they viewed themselves and how they feared others might view them. If Wilbur came to any harm they might view themselves—or others might view them—as incompetent, a view that is at odds with their preferred view that they are good care providers. Staff provided support for their theory by being able to see only one stereotypical, medical model perspective and they did not allow alternative views as to why Wilbur behaved the way he did. Only when staff went with Wilbur and found out why his behavior made sense to him were they led to respond to Wilbur's behavior in a way that fit his logic.

An alternative approach, one that would allow staff to align their preferred view of themselves, would be for them to recognize Wilbur's behavior as *problem solving*. Staff must identify Wilbur's behaviors as his attempt to use a successful solution, recalled from his unique life story, and apply it to his present situation. Though the behaviors he chose as his solution did not fit the time and place, they were close enough to fit the current context as Wilbur perceived it. Wilbur's best solution about what to do when he awoke at 2 A.M. was to be a responsible building superintendent and do what was required, but he still maintained his customary limitations. Although he was unable to orient himself to time and place, he relied on his remote memory to tap an adaptive response to the present context.

Wilbur's thinking was based on a view of the world that was determined by his experiences only, one that the staff's appeal to current reality (i.e., he was supposed to return to bed) was unable to modify.

Attempts at reality orientation are typically unsuccessful in similar cases with people who have AD; after sufficient cognitive decline, they lack the requisite cognitive function to decenter and adopt the other views of the world. Telling Wilbur that it was not time to get up and that the staff's view of reality was the correct one would only serve to confront him with his memory loss, an aspect of self for which he had no memory. These dueling paradigms are at the heart of many well-intentioned but ineffective interventions in AD care. They are the basis of the gap wideners that, for someone with AD, disconfirm the "self as now known" and fuel negative emotional states (Eron & Lund, 1996) so challenging to family caregivers and paid staff.

TELLING WILBUR THAT it was not time to get up and that the staff's view of reality was the correct one would only serve to confront him with his memory loss, an aspect of self for which he had no memory.

The staff was eventually able to view Wilbur's behavior as meaningful and, from his point of view, they were able to de-center from their view of his behavior and participate in his story and his solution in a helpful way. Reframing Wilbur's behavior from problem creating to problem solving allowed staff to align with his preferred view and support their own at the same time by displaying their helpful and competent selves. It also evoked aspects of Wilbur's self that limited the problem behavior at each occurrence and ultimately stopped it for good. The staff's comfort with Wilbur's use of solutions, drawn from strengths based in his unique history, increased as he acted according to this familiar nighttime pattern and provided the meaning that made them modify their theory of what motivated Wilbur's behavior, seeing it as problem solving rather than as problem creating.

A STRENGTHS-BASED, PERSON-CENTERED PERSPECTIVE OF MARY AND WILBUR

Each vignette attempted to demonstrate how the contrast in views and consequent interventions arising from them set the traditional analysis of behaviors apart from strengths-based, person-centered approaches. Each revealed how alternatives to the traditional approach provided opportunities for successfully resolving episodes of difficult behavior. The ability to place the origins of behavior in Mary's or Wilbur's desire to use their coping ability (albeit flawed due to the effect of dementia on cognition) provided the platform for collaborative problem solving based in the person's operative theory of self or preferred view. But more critically, it provided a win-win method for the preferred view of both the person with AD and the caregiver (family or paid) to confirm their respective preferred views.

SUMMARY

This chapter demonstrates the validity and value of a strengths-based, person-centered approach to AD and related dementia care. This approach is a complementary, synergistic construct that points the way for an individual to care for his or her *self* while coping with the effects of dementia. Above all, it is the responsibility of those who provide paid and unpaid care—and for the social institutions that represent sanctioned cultures of care and those who oversee them—to ensure that an individual's loss of self is not his or her price of care. Strengths-based, person-centered care is one way to prevent the excess disability that results when care providers focus on the person's illness and fail to "respond to fragile clues of selfhood" (Post, 1995). As Sabat and Harre observed, "as an organizing center, the 'self' is not lost even in much of the end stage of the disease" (1992, p. 460).

The following is a list of principles of high-quality dementia care (Bradley, Ronch, & Pohlmann, 1999) that captures the essence of strengths-based, person-centered ways to help people with AD and other related dementias. It is my hope that the reader will use these ideas to develop his or her own approach to caring for those with AD and related dementias through a creative application of these principles.

PRINCIPLES OF STRENGTHS-BASED CARE FOR PEOPLE WITH AD AND RELATED DEMENTIAS

- People with AD process information despite their cognitive impairments and do not experience their condition passively. They remain actively involved with both the external and internal (e.g., emotions, sensations, comfort) environments.
- Caring for people with AD is more effective and less difficult if their perspective and their "experiences of the illness" (Cotrell & Schulz, 1993) are included when formulating care approaches.
- People with AD, like the rest of us, have a preferred view that constitutes the basic operating assumptions and frames of reference that they use to interpret and give meaning to events in their lives.
- People with AD attempt to act in line with their preferred view as they try to cope with life's daily demands. Their preferred view typically may not include recognition of being cognitively impaired. Quality caring supports the preferred view reflected in coping attempts and tries to guide the person with AD toward successful coping responses that are in line with his or her preferred view.
- People with dementia try to make sense of their experiences so that they feel emotions and try to provide for themselves or seek from others solace when upset, meaning when confused, and self-esteem when dignity is compromised. They must increasingly make use of less recent, more remote historical information about their individual ways of coping in such circumstances; quality care helps provide a bridge to information so that the individual can cope to the best of his or her abilities.
- Problem behavior may be viewed as a sign that the person with AD is cognitively or emotionally overtaxed, is trying to solve a problem, is making sense of his or her experiences with information that is incom-

plete or "out of date" due to memory loss, and/or is having an unsettling emotional reaction to how he or she feels.

- Person-centered, strengths-based care reinforces self-esteem by providing the cognitive, emotional, and biographical information to enhance the individual's ability to be successful without first having to acknowledge his or her memory loss. Likewise, these behaviors are understood to originate in the mechanisms used by all humanity to cope rather than as signs of mental illness, willful misbehavior, purposeful malevolence, or moral failings.
- AD undermines the preferred view of the person with the disease, their family members, friends, and/or paid caregivers. As the disease progresses, they all experience the universal challenge to their long-held images of personal agency and competency as a result of the devastation of the illness and the corresponding loss of options they might normally use in the face of other illnesses to "fix it."
- Not all behavioral phenomena observed in people with AD are attributable to symptoms of dementia, per se, and thus, those who provide care can help achieve optimal quality of life by mobilizing the personal resources of the person with AD to achieve better adjustment to life with dementia.
- People with AD respond better and use their remaining strengths when they are presented with attractive opportunities to do things that fit their preferred view as adults than if they are faced with demands for mandatory participation in situations built around the illness paradigm in which everything is centered on therapy.
- Person-centered care mobilizes and makes optimum use of the strengths of people with AD and the people with whom they interact.

THE OBJECT OF CARE

The experience of a person with amnesia was characterized as his or her "having lost faith in actuality" (Palmer, 2000). If professionals provide care to people with dementia and other forms of amnesia amid a battle over actuality, they will win the battle and lose the war. The object of such care is the person (with dementia) as she knows him- or herself. The object is not to get the individual to see reality as others do, if only for a moment, before care is given. By doing that, one asks the person to lose faith in his or her own actuality—where the self still exists.

REFERENCES

Alzheimer, A. (1906). Uber einen eigenartigen schweren Krankheitsprozess der Hirnrinde [Remarks about a peculiar, severe disease process of the cortex]. *Neurologisches Centralblatt, 25,* 1134.

Alzheimer, A. (1907). Uber eine eigenartige Erkrankung der Hirnrinde [A peculiar disease of the cortex]. *Allegemeine Zeitschrift fur Psychiatrie, 64,* 146–148.

Blessed, G., Tomlinson, B.E., & Roth, M. (1968). The association between quantitative measures of dementia and senile change in the cerebral grey matter of elderly subjects. *British Journal of Psychiatry, 114,* 797–811.

Bowker, L. (1982). *Humanizing institutions for the aging.* Lexington, MA: Lexington Books.

Bradley, A.M., Ronch, J.L., & Pohlmann, E. (1999). The EDGE project. Retrieved from Dementia Solutions Web site: http://www.dementiasolutions.com.

Buber, M. (1970). *I and thou.* New York: Charles Scribner's Sons.

Cohen, D., Kennedy, G., & Eisdorfer, C. (1984). Phases of change in the patient with Alzheimer's dementia: A conceptual dimension for defining health-care management. *Journal of the American Geriatrics Society, 32*(1), 11–15.

Cohen, D., & Eisdorfer, C. (1986). *The loss of self: A family resource for the care of Alzheimer's disease and related disorders.* New York: Norton.

Cohen, G. (1997). Progress in Alzheimer's disease-pause and perspective. *American Journal of Geriatric Psychiatry, 5,* 185–187.

Cohen-Mansfield, J. (2000). Theoretical frameworks for behavioral problems in dementia. *Alzheimers Care Quarterly, 1*(4), 8–21.

Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A dimension of dementia research. *The Gerontologist, 37,* 205–211.

Cousins, N. (1974). *Anatomy of an illness as perceived by the patient.* New York: W. W. Norton and Company.

Cousins, N. (1989). *Head first: The biology of hope.* New York: E.P. Dutton.

Damasio, A. (1994). *Descartes' error.* New York: Avon Books.

Damasio, A. (1999). *The feeling of what happens.* New York: Harcourt Brace.

Eron, J., & Lund, T. (1996). *Narrative solutions in brief therapy.* New York: Guilford Press.

Fagan, R., Williams, C., & Burger, S. (1997, October 1). *Meeting of pioneers in nursing home culture change: Final report.* Privately distributed by the authors.

Feinberg, J. (Ed.). (2000). Medication and aging. *Generations, 24,* 4.

Feinberg, T. (2001). *Altered egos: How the brain creates the self.* New York: Oxford University Press.

Folstein, M.E., Folstein, S.E., & McHugh, P.R. (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189–198.

Fox, P. (1989). From senility to Alzheimer's disease: The rise of the Alzheimer's disease movement. *The Milbank Quarterly, 67*(1), 58–102.

Frank, A.W. (1996). *The wounded storyteller: Body, illness and ethics.* Chicago: University of Chicago Press.

Gadamer, H. (1993). *The enigma of health: The art of healing in a scientific age* (Translated by J. Geiger & N. Walker). Stanford, CA: Stanford University Press.

Gerdner, L. (2000). Effects of individualized versus classical music on the frequency of agitation in elderly persons with Alzheimer's disease. *International Psychogeriatrics, 12*(1), 49–65.

Goldfarb, A. (1961). Current trends in the management of the psychiatrically ill aged. In P.H. Hoch & J. Zubin (Eds.), *Psychopathology of aging* (pp. 248–265). New York: Grune & Stratton.

Goldfarb, A. (1969). The psychodynamics of dependency and the search for aid. In R.A. Kalish (Ed.), *The dependencies of old people* (pp. 1–15). Ann Arbor: Institute of Gerontology, University of Michigan.

Goldfarb, A. (1974). Institutional care of the aged. In E.W. Busse & E. Pfeiffer (Eds.), *Behavior and adaptation in later life* (pp. 264–292). Washington, DC: American Psychiatric Association.

Goldsmith, M. (1996). *Hearing the voice of people with dementia: Opportunities and obstacles.* London, England: Jessica Kingsley Publishers.

Holmes, D., Ory, M., & Teresi, J. (1994). Special dementia care: Research and practice issues. *Alzheimers Disease and Associated Disorders: An International Journal, 8*(Suppl. 1).

Katzman, R. (1976). The prevalence and malignancy of Alzheimers disease. *Archives of Neurology, 33,* 217–218.

Katzman, R., & Karasu, T. (1975). Differential diagnosis of dementia. In W. Fields (Ed.), *Neurological and sensory disorders in the elderly* (pp. 103–134). New York: Intercontinental Medical Book Corp.

Katzman, R., Terry, R., & Bick, K. (1978). *Alzheimer's disease: Senile dementia and related disorders.* New York: Raven Press.

Kennedy, G. (1995). The geriatric syndrome of late-life depression. *Psychiatric Services, 46*(1), 43–48.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham, England: Open University Press.

Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition.* New York: Basic Books.

Lawler, B. (1995). Possible neurological basis for behavioral symptoms. In B. Lawler (Ed.), *Behavioral complications in Alzheimer's disease* (pp. 91–127). Washington, DC: American Psychiatric Press.

Luria, A. (1985). In O. Sacks, *The man who mistook his wife for a hat* (p. 32). New York: Summit Books.

Lyman, K. (1989). Bringing the social back in: A critique of the biomedicalization of dementia. *The Gerontologist, 29,* 597–605.

Mace, N., & Rabins, P. (1981). *The thirty-six hour day.* Baltimore: The Johns Hopkins University Press.

Maletta, G. (1992). Treatment of behavior symptomatology in Alzheimer's disease with emphasis on aggression: Current clinical approaches. *International Psychogeriatrics, 4*(Suppl. 1), 117–130.

Morris, D. (2000). *Illness and culture in the postmodern age.* Berkeley: University of California Press.

Palmer, T. (2000). Dream science. In J. Lethem (Ed.), *The Vintage book of amnesia* (pp. 3–20). New York: Vintage Books.

Pierce, C.P. (2000). *Hard to forget.* New York: Random House.

Post, S. (1995). *The moral challenge of Alzheimers disease.* Baltimore: The Johns Hopkins University Press.

Roach, M. (1985). *Another name for madness.* Boston: Houghton Mifflin.

Rogers, J., Holm, M., Burgio, L., Hso, C., Hardin, J.M., & McDowell, B.J. (2000). Excess disability during morning care in nursing home residents with dementia. *International Psychogeriatrics, 12*(2), 267–282.

Ronch, J. (1987). Specialized Alzheimer units in nursing homes: Pros and cons. *American Journal of Alzheimers Care and Related Disorders and Research, 2,* 10–19.

Ronch, J. (1996). Assessment of quality of life: Preservation of the self. *International Psychogeriatrics, 8,* 267–275.

Ronch, J., & Crispi, E.L. (1997). Opportunities for development via group psychotherapy in the nursing home. *Group, 21*(2), 135–158.

Sacks, O. (1985). *The man who mistook his wife for a hat.* New York: Summit Books.

Salovey, P., Rothman, A., Detweiler, J., & Steward, W. (2000). Emotional states and physical health. *American Psychologist, 55*(1), 110–121.

Scheibe, K. (1989). Memory, identity, history and the understanding of dementia. In L. Thomas (Ed.), *Research on adulthood and aging; The human science approach* (pp. 141–162). Albany: State University of New York Press.

Taylor, S., Kemeny, M., Reed, G., Bower, J., & Greenwald, T. (2000). Psychological resources, positive illusions and health. *American Psychologist, 55*(1), 99–109.

Teresi, J., Lawton, M.P., Ory, M., & Holmes, D. (1994). Measurement issues in chronic care populations: Dementia special care. In D. Holmes, M. Ory, & J. Teresi (Eds.), Special dementia care: Research and practice issues. *Alzheimers Disease and Associated Disorders: An International Journal, 8*(Suppl.1).

Teri, L., & Gallagher-Thompson, D. (1991). Cognitive-behavioral interventions for treatment of depression in Alzheimer's patients. *The Gerontologist, 31,* 413–416.

Terry, R.D. (1963). The fine structure of neurofibrillary tangles in Alzheimer's disease. *Journal of Neuropathology and Experimental Neurology, 22,* 629–634.

Torack, R. (1983). The early history of senile dementia. In B. Reisberg (Ed.), *Alzheimers disease: The standard reference* (pp. 23–28). New York: The Free Press.