An Adlerian Framework for Encouraging Dementia Resilience

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By:

Judith Pinke

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Abstract
Current victim-centric and medicalized approaches to dementia care are inadequate to minimize human and financial costs, especially given predictions of large increases in numbers of people who experience this disorder. Most people with dementia, their caregivers, and their families struggle within society’s dominant constructions about the personal impact of the dementia experience. A new therapeutic point of view that supports efforts to thrive despite the challenges that can be associated with dementia will create a foundation of social justice for these people. Adlerian psychology, integrated with resilience theory, provides a framework to help people find meaning and clarify their movement, that is, their purposive behavior, as well as to increase their courage to persist. In encouraging dementia resilience, meaning, movement, and courage are the vehicles for thriving and personal growth. Through coping rather than reacting, adapting relationships rather than withdrawing, and growing rather than endlessly repeating unsuccessful behaviors, people can find that this journey, while arduous, need not dead-end at diminishment and suffering.
Table of Contents

Abstract

An Adlerian Framework for Encouraging Dementia Resilience

The Dementia Challenge

Societal Costs

The Personal Impact

   Overcoming the stigma.

   Notions of dementia identities.

   \textit{Person with dementia}.

   \textit{Caregiver}.

   \textit{Family}.

Adlerian Framework

Meaning

Movement

Courage

Resilience Theory

Research Definitions of Resilience

   Protective factors.

   Traits.

   Positive adaptation.

Resilience as Thriving

   Resilience as regulation of emotion.

   Resilience as the norm.
Resilience as adult developmental opportunity.

Resilience as psychological capacity.

A New Construct of Resilience

Resilience within the Adlerian Framework

Behaviors: Resilient or Discouraged

Coping.

Adapting.

Aggressive discouragement.

Other aggressive antisocial behaviors.

Growing.

Encouragement through Emotion

Approaches to Encouraging Dementia Resilience

Encouraging through a Helping Relationship

Therapy as encouragement.

Joining people on a dementia journey.

Encouraging Resilience in the Person with Dementia

Human needs.

Need to belong.

Need to be safe.

Need to matter or be significant.

Social interest.

Assessment.

Cooperation.
Communication.

Relationship.

Emotion.

Well-being.

Meaning.

Understanding meaning.

Recognizing identity as meaning.

Viewing identity as a social construct.

Movement.

Coping-reacting.

Adapting-withdrawing.

Growing-endlessly repeating.

Courage.

Encouraging the person with dementia.

Encouragement as contributing rather than competing for perfection.

Encouragement as joining.

Encouraging Resilience in the Caregiver

Importance of Caregiver Resilience.

Assessment.

Assessment tools.

Protective factors.

Traits.

Adaptation.
Adlerian approach to assessment.

Meaning.

Existential meaning.

Sense of coherence.

Dementia uncertainties.

Alternative cultures of dementia care.

Common themes about the caregiving experience.

Ambiguous loss.

Present psychologically but not here physically.

Present physically but not psychologically here.

Ambiguous difference.

Meaning as making sense.

Movement.

Coping-reacting.

Nature of dementia illnesses.

Changed modes of interaction.

Financial issues.

Direct caregiver impacts.

Adapting-withdrawing.

Changed relationships.

Safety of person with dementia.

Decision-making.

Growing-endlessly repeating.
Courage.

Encouraging the dementia caregiver.

Encouraging Resilience in the Caregiver-Care Partner Dyad

Assessment—images of health.

*Individual and couple are resilient and show courage.*

Resilient.

Less resilient, type 1.

Least resilient, type 1.

Less resilient, type 2.

Least resilient, type 2.

*Relational behaviors demonstrate working together.*

Resilient.

Less resilient, type 1.

Least resilient, type 1.

Less resilient, type 2.

Least resilient, type 2.

*Communication works to attainable level.*

Resilient.

Less resilient, type 1.

Least resilient, type 1.

Less resilient, type 2.

Least resilient, type 2.

*Roles and boundaries in health care situations support medical and mental health.*
Resilient.

Less resilient, type 1.

Least resilient, type 1.

Less resilient, type 2.

Least resilient, type 2.

Mix of interdependent, dependent, and independent interactions supports balanced quality of life.

Resilient.

Less resilient, type 1.

Least resilient, type 1.

Less resilient, type 2.

Least resilient, type 2.

Meaning.

Movement.

Responses to mistaken goals of behavior.

Resilience and areas of intimacy.

Courage.

Encouraging the relationship.

Encouraging Resilience in the Family

Assessment.

Stage of family development.

Phase of the journey.

How the family works.
Adlerian assessment.

Meaning.

Movement.

Coping-reacting.

Adapting-withdrawing.

Growing-endlessly repeating.

Courage.

Encouraging the family.

Collaborative learning.

Community that encourages resilience.

Summary of Encouraging Ways of Being

References

Figures

1: Elements of Adlerian Lifestyle and Their Inter-Relationships

2: Two Sides of Courage/Discouragement Coin

3: Dance of Discouragement/Encouragement
An Adlerian Framework for Encouraging Dementia Resilience

The understanding is growing that when one family member has dementia, the whole family is on a dementia journey (Caron, Pattee, & Otteson, 2000). It is clear that such a journey is wrenching for the person with dementia as well as for caregivers and family members. “Dementia breaks into the previously routine lives of individuals and families, like a tidal wave disrupting everything in its path. The person with dementia is eventually swept away, while caregivers look back and feel forever changed by their experience” (Post, 2000, p. 2).

The mental health challenge in dementia work is to help people who are on a dementia journey to find their resilience for an arduous trip that, nonetheless, is a potential developmental opportunity. The practice- and research-based program described below, Encouraging Dementia Resilience, supports the person with dementia, caregivers, and family members and provides guidance for professional helpers who interact with people on a dementia journey.

The hallmarks of dementia are losses in cognitive function including memory and at least one other area among (a) speech and language use, (b) object recognition, (c) motor abilities, and (d) thinking skills like abstraction, judgment, and executive functions, i.e., planning and carrying out complex tasks. While damaged brain cells are the proximate cause of dementia symptoms, researchers such as Kitwood (1997) theorize that a partial explanation for the progression of the disease is the social responses to the person with dementia.

Describing the dynamic that may underlie that social reaction, Caron (1997) suggests “because the disease attacks the capacity to remember, understand, and reason, those afflicted with the disorder become alienated from the coping process. They become objects of caregiving” (p. 314). People viewed as objects of another’s actions may indeed become less fully stimulated cognitively and emotionally and, therefore, progress in the disease.
“Noncognitive neuropsychiatric symptoms are nearly universal in people with dementia . . . and include agitation, aggression, delusions, hallucinations, repetitive vocalizations, and wandering, among others” (American Association for Geriatric Psychiatry, 2005, p. 8). Such symptoms surely contribute to the social unease about the status of people with dementia as well as uncertainty about how to be with them.

In a 2009 report about dementia in the United States, the Alzheimer’s Association (AA) describes eight common types of dementia: Alzheimer’s disease, vascular dementia, mixed dementia, dementia with Lewy bodies, Parkinson’s disease, frontotemporal dementia (FTD), Creutzfeldt-Jakob disease, and normal pressure hydrocephalus. Diagnoses may overlap because symptoms overlap. Increasingly, according to AA, reliable evidence shows an overlap of brain characteristics across some types of dementia.

In terms of predicting impact on the life of the person with dementia, it is important to recognize that, despite a specific diagnosis, each person, each progression, and each response combine to create a unique path for the person and his or her caregiver and family members. Because dementia physically presents differently in different brains and strikes at key elements of the social constructs of personality, it is highly individuated.

Consequently, it is critical to approach support and treatment with understandings of the psychology of the individual and of the system of his or her relationships. In keeping with such an approach, this paper describes the dementia challenge, an Adlerian framework, resilience theory, resilience within the Adlerian framework, and approaches to encouraging dementia resilience. It also provides a summary of ways of being with people on a dementia journey.

**The Dementia Challenge**

The impact of dementia is societal and personal. Alzheimer’s Disease International (ADI,
2009) reports a global economic and social cost estimated at $315.4 billion, with a prevalence estimate of 29.4 million people with dementia. This number will rise, according to ADI (2008), to over 100 million by 2050. Such statistics reveal why dementia is like a tsunami, arising from the earthquake of aging populations worldwide.

People with dementia in developing countries account for more than 60% of the worldwide total, and by 2040 their proportion will reach 71% (ADI 2009). In the United States, 5.3 million Americans (including one in eight people who are age 65 or older) currently have Alzheimer’s disease (AA, 2009).

Alzheimer’s accounts for only 60 to 80% of dementia cases. Consequently, 6.6 to 8.8 million Americans have some form of dementia. This includes approximately 500,000 under age 65. Rabins (2008) predicts an estimate of 16 million Americans with Alzheimer's by 2050. The Alzheimer Society of Canada (as cited in CTVglobemedia, 2008) reports a half million Canadians with dementia with an anticipated increase within 5 years of an additional quarter million.

AA (2009) estimates that, in 2008, 2.4 million women and 1 million men aged 71 and older had dementia. The higher number for women is a result of women’s longer life expectancy. The Framingham study (as cited in AA) found the estimated lifetime risk of women reaching the age of 65 to develop dementia was 20%, compared to approximately 17% of men. AA regards the estimates as very conservative, with people at risk “far exceed[ing] those stated in the Framingham study” (p. 13). It is also estimated that across the country, states and regions will experience double-digit percentage increases in numbers of people with Alzheimer’s from 2000 and 2025. This will include great variability in a range that rises to more than 80% for nine states, which is primarily due to variation in where the elder population resides. The projection
for Minnesota’s increase is 25%.

AA (2009) also reports mortality data, such as a 2005 nationwide rate of Alzheimer’s deaths at 23 per 100,000. U.S. deaths from Alzheimer’s disease reached almost 72,000 in 2005 and increased about 47% between 2000 and 2006. At the same time, other diseases have shown reductions: stroke, 18%; prostate cancer, 14%; heart disease, 12%; breast cancer, 1%. “The mechanisms by which dementia leads to death may create ambiguity about the underlying cause of death” (AA, p. 27), so Alzheimer’s deaths are likely underreported.

**Societal Costs**

Unpaid caregivers for people with dementia are most often family members. Rabins (2008) reports that more than 70% of people with Alzheimer's disease live at home and that unpaid caregivers provide almost 75% of their care. In 2008, 9.9 million Americans were unpaid caregivers for a person with dementia, contributing a total of 8.5 billion hours, valued at $94 billion (calculated at $11.10 per hour, which was the average of the minimum wage and the average home health aide wage) (AA, 2009). In Minnesota in 2008, 176,000 caregivers provided 152 million hours of care valued at $1.7 billion (same calculation method).

AA (2009) also reports how costly health care is for people with dementia. Using as a proximate population the pool of Medicare beneficiaries aged 65 and older in 2004, AA calculated the cost per person for health and long-term care was three times higher for those with dementia than for others ($33,007 versus $10,603). In 2005, direct costs to Medicare and to Medicaid for care to people with dementia were $91 billion and $21 billion respectively. The indirect cost to businesses for employees who were caregivers was $36.5 billion. Thus, the cost in 2005 totaled $148 billion.

Another way to look at the social cost of health care and long-term care for people with
dementia is to compare them by type of health care service to those without dementia. AA (2009) reports the average Medicare payment to beneficiaries with dementia age 65 and over in 2004 to be 9.1 times higher for skilled nursing facility, 4.5 times higher for home health care, 2.8 times higher for hospital care, 1.5 times higher for prescription medications, and 1.4 times higher for medical providers.

Paying for long-term care is often a public obligation. In 2005, 57% of older people in the community and 75% of those at high risk of needing care in a nursing home had insufficient assets to cover a month in a nursing home (AA, 2009). Until medical science provides prevention or cures for the dementias, the primary hope for forestalling astronomical costs as the baby-boomer cohort ages is to create interventions that reduce the rate of institutional long term care and increase the effectiveness of home-based, unpaid care—without adding to the impact on caregivers.

The Personal Impact

In addition to the issue of societal cost is the matter of normative beliefs about people with dementia and their caregivers. A vigorous social justice strategy would repair socially-prevalent constructs about dementia. These constructs include identity loss, caregiver burden, depression and anxiety, hopeless conflict, impossible behaviors, lack of communication, and family disruption. Instead, a more healthful, whole-person/whole-family model is needed, one that promotes thriving, intimacy, and cooperation.

Overcoming the stigma. A recent uproar in the British press emphasizes the need for a social intervention. A statement by Helen Mary Warnock, a British medical ethicist and government advisor, stimulated the print and electronic furor:

If you’re demented, you’re wasting people’s lives—your family’s lives—and
you’re wasting the resources of the National Health Service. I’m absolutely, fully in agreement with the argument that if pain is insufferable, then someone should be given help to die, but I feel there’s a wider argument that if somebody absolutely, desperately wants to die because they’re a burden to their family, or the state, then I think they too should be allowed to die (as cited in Beckford, 2008, p. 1).

While inflammatory misinterpretations of “a duty to die” and “being put to death” stimulated the resulting media uproar, Warnock’s statement nonetheless encapsulates a widely held assumption that people with dementia are lesser beings because of their cognitive changes.

The grounding principle of encouraging dementia resilience is fostering new ways of looking at the dementia experience. For instance, Post (2000) calls for “overcom[ing] the stigma associated with dementia, principally by being with deeply forgetful persons in attentively caring ways that draw upon their remaining emotional, relational, and creative capacities” (p. 3). Encouragement allows caregivers, family members, and professional helpers to build on those capacities. This strategy increases quality of life for the person with dementia.

**Notions of dementia identities.** One of the contributions of narrative therapy is showing how therapeutic work must include the influence of culturally-dominant constructions of self (Brown & Augusta-Scott, 2007). Essentialism is the term for assumptions that are taken for granted in dominant social discourse about a particular group of people.

**Person with dementia.** Today’s dominant stories characterize the essence of people with dementia as victims who exhibit random and purposeless behavior; who lose their identities and value; and who merely wait to die as the wards of their caregivers and medical or long-term-care environments. They are also, in view of cognitive decline and progressive dependence,
stigmatized within a society that values independence, productivity, and rationality.

Instead, we can come to understand that people with dementia remain unique individuals, often unpredictable in their behaviors but always retaining a purpose for them. They can be fully alive at emotional, relational, and creative levels until far into the course of the disease. Caron (1997), in working with a group of people with dementia, affirms who they are: “Given the right setting, the unique personalities of those with dementia stand forth and shine. . . . Although dementia has stolen much from [them], they are not absent but rather changed. Accepting these changes opens possibilities for continued positive involvement in their lives” (p. 323).

**Caregiver.** The common view in today’s social constructions is that caregivers of people with dementia are, in their essence, victims of the disease, too. Common views are that they have impossible burdens and that they necessarily put their lives on hold as they are swallowed by their responsibilities. The typical social construct is that they have no control over the progression of the disease experience and no options or choices for roles to play. From this perspective, they appear trapped in an endless stream of meaningless and menial tasks.

This social construct extends to two poles. At one extreme, caregivers hear that they are uncaring if they place the person with dementia in long term care. At the polar opposite, society sees them as sentimental martyrs if they opt to keep the loved one in the home environment until and perhaps through hospice stages.

Instead of settling for caregiving as a time-out from living, caregivers can come to thrive, grow, and creatively adapt to challenges of both learning and doing. Caregivers can find many options and choices, and they can develop supportive networks of assistance and respite to help them along the way. Above all, they “create a value framework and sphere of care in which people with dementia can be interpreted as being worthy of well-being” (Post, 2000, p. 33).
**Family.** The common view of families on the dementia journey is that they will carry forward their old family identities, roles, rules, and conflicts. Often there is little understanding that the old family ways can be a source of strength if reinterpreted. Resolution of the old relationships, in society’s essentialist view, proceeds by solving long-standing relational problems in order to carry out caregiving and decision-making. In this view, there is a right way for family members to respond based on the family of origin.

Frequently, everyone claims an equal voice in decision-making, even though they do not equally share the work. Often the assumption is that the female, the unmarried, or the local (geographically proximal) family member is suitable and responsible to be the primary caregiver. In the final division of duties, family members who are unresponsive to the family challenges are excused, not simply based on the persistence of their refusal to engage, but more often based on long-held family beliefs and roles.

Instead, families dealing with dementia can be less concerned with curing the family and more concerned with maintaining or improving communication, emotional reciprocity, and relationships with the person with dementia. A family’s goal can be to “challenge existing social arrangements and create within their own circle and in institutional forms a hospitable milieu for people with this progressive disability” (Post, 2000, p. 33). They, most healthily, open their boundaries in the formation of what Boss (2006) calls them to attend to, the psychological family. In addition, families become “sociopolitical [and medical system] advocates for affected individuals, who, with waning powers of articulation and will, are politically voiceless and therefore vulnerable” (Post, p. 33).

**Adlerian Framework**

The work of Alfred Adler provides a psychological framework within which to support a
new type of dementia journey. Adler recognized humans as social beings, embedded from their birth within a social context in which they carry out their lives (Ansbacher & Ansbacher, 1964). The three tasks or challenges of life are all social in nature—work, love (or sex), and friends (or communal effort). Later, Dreikurs and Mosak added two more tasks: relationship to self (1967a) and spiritual, existential, or search for meaning (1967b). Yet Adler’s original conception of the life tasks is that they are social in nature. Dreikurs (1972) points out that “all human qualities are expressions of social interaction” (p. 43).

Adlerian psychology focuses on a person’s unique lifestyle. “The style of life arises in the child out of his [or her] creative power, i.e., from the way he [or she] perceives the world and from what appears to him [or her] as success” (Adler, 1957, p. 10). The lifestyle is the expression of the unity and self-consistency of the personality.

Adler (1931b) asserted that a prototype of the lifestyle is developed through infancy into early childhood (by age four or five) in response to a feeling of inferiority that the child tries to overcome. In actuality, a child is inferior, small, weak, and incomplete in the face of life. Therefore, the inferiority feeling is a hallmark of all humans, and their striving to overcome this feeling serves as motivation for all people.

Children develop their lifestyles under the influence of their family systems. The constellation of the family of origin includes birth order and distribution of predominant and gender roles in the family. Family atmosphere includes parenting style, collective social interest, family private logic, and the family’s fictional goal. In effect, each family has a lifestyle, and it is within that lifestyle that the child constructs his or her own lifestyle. According to Sherman and Dinkmeyer (1987), nine structural and functional elements of families interact to create the family dynamics: power, boundaries and intimacy, coalitions, roles, rules, complementarities and
differences, similarities, myths, and patterns of communication. The family system is a critical influence on the individual lifestyle.

Adlerian tools uncover eloquent clues to the fictions and biased apperceptions people hold and upon which they found the convictions that, absent an exogenous event, will direct the life-long guiding line. Therapeutic intervention can be one such event. Encouragement, person to person, is an even greater stimulus to the central Adlerian concept of mental health—cooperation or social interest.

Three organizing concepts that are critical to understanding Adlerian individual psychology are meaning, movement, and courage. From his or her convictions and biased apperceptions, the child develops beliefs that provide foundation to his or her consistent pattern of behaviors. Figure 1 displays the elements of lifestyle and the inter-relationships among those elements.

**Meaning**

Adler was clear in the role of meaning: “meanings are not determined by situations, but we determine ourselves by the meanings we give to situations” (as cited in Adler Graduate School, July 2009). Children establish the basis for lifelong meaning in their lives as they try to make sense of self, others, and the world. Interpretations and experiments abound as they develop the fictions and apperceptions that underlie the meanings they have “found in [their] existence and how [they] propose to realize that meaning” (Ansbacher & Ansbacher, 1964, p. 96).

The child also develops a goal that is a self-ideal or an image of success. The person’s lifestyle comprises the beliefs and goals. They are fictions created by the child, who will act throughout his or her life as if they were true representations of reality. The child ignores,
forgets, or misperceives anything that does not fit the lifestyle. The person’s lifestyle is “a cognitive framework within which he [or she] selects the specific operations which enable him [or her] to cope with life tasks” (Mosak, 1971, p. 77).

A child’s beliefs may be based on private logic, that is, “hidden or unconscious reasons for feeling, thinking, and behaving as we do” (Oberst & Stewart, 2003, p. 25) or on common sense, “all values, ideas and concepts which we share with other members of our group” (Dreikurs, 1967, p. 210).

How fully a person meets and balances the three challenges of life is a measure of the amount of social interest the person demonstrates. “Social interest is the true and inevitable compensation for all the natural weaknesses of individual human beings” (Ansbacher & Ansbacher, 1964, p. 154). It is “to see with the eyes of another, to hear with the ears of another, to feel with the heart of another” (Ansbacher & Ansbacher, p. 135).

Ansbacher and Ansbacher (1964) describe social interest as an aptitude through which the person can respond in a useful way to the social situation. They also refer to it as “social feeling, community feeling, fellow feeling, sense of solidarity, communal intuition, community interest, social sense” (p. 134). “Just as striving from a minus to a plus situation—toward overcoming, success, superiority, or perfection—is the master motive in Adler’s psychology, so social interest is the cardinal personality trait, with traits regarded as reflecting ‘the relationship of an individual to his [or her] environment’” (Ansbacher, 1968, p. 131).

**Movement**

To Adler, movement is all (Ansbacher & Ansbacher, 1964). Adlerians consider movement as:

all thought, feeling, and physical activity. . .; [it] connotes the understanding of a human
being as always in process, moving away from the felt minus toward a subjectively-conceived fictional plus position, away from the intolerable feelings of worthlessness toward the desired feelings of mastery and worthwhileness. (Griffith & Powers, 2007, p. 79)

In effect, a person is “not a thing but a performance” (Flannery, as cited in Griffith & Powers, p. 107). There is a simple rule that applies to all persons: look at what a person does, not what he or she says. Adlerians have rephrased this as ‘trust only movement’” (Carlson, Watts, & Maniaci, 2006).

According to Adler (1933), “every individual is seized by the striving for perfection, by the upward striving. . . [which] is innate as something which belongs to life, a striving, an urge, a developing, a something without which one could not even conceive of life” (p. 31).

People have a will to be safe, to belong, and to matter or be significant. All behavior (thinking, feeling, acting, intending) is along a line of movement, that is, behavior is purposive. All behavior is striving toward the fictive goal—whether consciously so or not. “We cannot think, feel, will or act without the perception of some goal. . . . All psychic activities are given direction by means of a previously determined goal” (Adler, 1959, pp. 3-4). Sweeney describes purposive behavior as that which “serves a use for the individuals to pursue their goals” (1998, p. 25). To understand the purpose of a behavior, look at the result.

In Adlerian theory, behaviors are symptoms. They are not targets of change but avenues to understanding the purpose that lies beneath the symptom. Adler (as cited in Ansbacher & Ansbacher, 1964, p. 330) states:

We look upon symptoms as creations, as works of art; . . . we must find in every symptom something that lies deeper than the outward and visible signs, . . . for behind
lies something more, something personal and entirely individual. . . . No symptom observed in two different cases has ever exactly the same significance. But there is one assumption we can make in all cases: a symptom is connected with the individual’s struggle to reach a chosen goal.

Adult behaviors may not work within the adult social context because of (a) the goal developed in childhood, (b) mistaken beliefs created from the inadequacies of a child’s cognitive skills, emotional development, or imprecise observation, or (c) the biases built into his or her interpretations of results of behaviors. These behaviors, in the medicalized mental health system, have been categorized as depression, anxiety, neurosis, personality disorder, etc. From an Adlerian perspective, categories are not important; movement is.

R. A. Ballou (personal communication, July 26, 2009) describes such categories as clusters of symptoms. Adler comments that “all neurotic symptoms are safeguards of persons who do not feel adequately equipped or prepared for the problems of life, who carry within themselves only a passive appreciation of social feeling and interest” (1932b, p.95). The symptoms are a response to an underlying problem about which the person is discouraged.

Courage

Movement alone is not courage. Courage is exhibited as movement against the “universally experienced inferiority feelings of incompleteness, of being below, of being in a position of ‘less than’ the others, or less than what life requires or allows” (Griffiths & Powers, 2007, p. 39). When a person has courage, he or she compensates in socially useful ways, that is, takes direct action to improve the situation.

The most obvious sign to identify courage is cooperation. Adler (Ansbacher & Ansbacher, 1979) emphatically states that “activity should not be confused with courage,
although there is no courage without activity. But only the activity of an individual who plays the game, cooperates, and shares in life can be designated as courage” (p. 60). In the Adlerian view, the majority of mental health diagnoses are indicators of discouragement. How the discouragement presents depends on the unique lifestyle of the individual.

In a child, courage may diminish if attempts to take action do not decrease the sense of personal inferiority. As life proceeds, the person may become discouraged if his or her striving (to be safe, belong, be significant—thus to overcome the sense of inferiority) is not bringing him or her to the fictive goal. Sometimes the compensatory striving for superiority over their inferiorities becomes striving for power over others—superiority for its own sake (Oberst & Stewart, 2003).

“A discouraged person. . . experience[s] feelings of inferiority and tend[s] to cling to attitudes and convictions more dogmatically because the individual attained a false and elusive sense of security from them” (Krause, 1959, as cited in Mosak & Maniacci, 1998, p. 75). For instance, if people’s behaviors seem to meet their purpose of elevating themselves by putting someone else in a subordinate or inferior position, other people may resist taking the inferior position. People rarely find security in behaviors that others do not accept, and yet they may be hard-pressed to change the convictions that lead them to those behaviors. They become discouraged.

Discouragement shows up in behaviors that attempt to safeguard people from feeling inferior. To safeguard is to behave in a way that protects self-esteem. This can include distancing from the challenge or from others through retreating, standing still, hesitating, or building obstacles (often composed of his or her symptoms) to taking on the challenge. To safeguard is to move away from the challenge and, in doing so, to meet the purpose of
eliminating the threat that one may be inferior to the challenge (J. M. Reardon, personal communication, October 14, 2009). Discouraged people can also create pre-emptive excuses, known as “buying insurance,” or set up a sideshow to distract attention.

“The ‘safeguarding devices’ used by an individual are invariably methods and patterns tried and tested from early childhood on, in one form or another (Adler, K. A., 1963, as cited in Beames, 1992, n. p.). The person attempts to carry out a pretense of superiority over the challenge through safeguarding or even through a conscious excuse for not attempting—all in service to the fear of imperfection.

Whether behavior arises out of courage or discouragement, look at the results of behavior to understand purpose. Understanding purpose is the key to recognizing mistaken beliefs. Recognizing mistaken beliefs is the key to encouraging psychological change. People can be encouraged to work out the mistaken beliefs that hold the discouragement in place.

“Technically, encouragement is conceptualized as instilling positive expectations into the schematic framework of the person” (Mosak & Maniacci, p. 75).

Resilience Theory

The study of resilience has its roots in research about children or the childhoods of specific adult populations. For instance, Spitz studied institutionalized children whose symptoms would now be described as reactive attachment disorder (1945, as cited in De Bellis, 2005). Werner and colleagues examined adults who as children had been born into poverty (1971, 1977, 1982, 1992, 2001, as cited in Johnson & Wiechelt, 2004). Garmezy (1971, 1987) studied children who would be expected to develop psychopathology as adults. Studies of children with other risk factors are described in a review by Masten (1994, as cited in Johnson & Wiechelt).
Early efforts searched for extraordinary traits of children who did well or for features in their environments that predicted that they would do well in life challenges. Cicchetti and Garmezy (1993) trace the roots of resilience research to studies of schizophrenia, poverty, and response to trauma, with recent research in developmental psychopathology yielding results on resilient outcomes.

According to Wright (2005), the study of resilience proceeded in several waves. The first wave focused on the individual, the second took a developmental-systems approach to positive adaptation, the third, “now taking shape, is focused on creating resilience by preventive interventions, directed at changing developmental pathways” (p. 17). Masten (2007) reports the appearance of a fourth wave that focuses on the systemic dynamics of adaptation and change.

Walsh (2003) reports that most research has dealt with the concept of individual rather than family resilience and that, in the early resilience literature, “families [were] seen to contribute to risk, but not to resilience” (p. 2). Her resilience work focuses on the ability of the family system to respond in times of crisis to foster recovery of all members and the family system, not so much in terms of “bouncing back” to the original state as in “bouncing forward” (p. 10). She incorporates the ability to “struggle well” (p. 1) and describes resilience as processes in which families engage.

Hawley (2000) describes the increasing visibility of resilience in the field of family therapy, beyond its role as a protective factor for youth.

**Research Definitions of Resilience**

The construct of resilience is being pursued in many subfields of research: child development, childhood neglect or abuse, parenting, role of schools, adult stress resistance, ambiguous loss, trauma and post-traumatic stress, elder cognitive strategies, caregiver strengths,
the neurobiology of emotional affect, and brain plasticity. The approaches of disparate researchers and popularizers of the concept reflect in their descriptions of resilience, its sources, or its absence.

Almedon and Glandon (2007) summarize the different things resilience means to different researchers as “a process, an outcome, a dynamic steady state in the face of adversity, and defiance of risk/vulnerability” (p. 127). The threads from the many research approaches have yet to be woven together into an integrated definition of resilience. A simple separation of resilience definitions is into protective factors, traits, and positive adaptation.

**Protective Factors.** A great deal of research attempts to ferret out the protective factors that seem to help people from high-risk groups to achieve better results than would be predicted from environmental factors. Benard (2004) identifies protective factors from family, school, or community programs that fall in three categories: caring and support, high expectations, and participation/contribution.

Tedeschi and Kilmer (2005) describe protective factors of (a) a nurturing family, quality parenting and a stable home, and a good relationship with a primary caregiver; and (b) a broader positive context such as extrafamilial support and identification models, links with extended family, effective schools, involvement with social organizations, and a quality neighborhood.

It is common to find such lists of variables in the research literature. While protective factors are helpful to challenge society to provide children and adolescents with strong environments, they ignore what is going on inside the child or teenager to create personal strengths and resolve.

**Traits.** Benard (2004) compares 15 versions of research or theory on personal strengths to synthesize resilience as traits of social competence, problem-solving, autonomy, and purpose.
or future orientation. Tedeschi and Kilmer (2005), in an attempt to synthesize part of the literature, report that individual attributes or characteristics appear to facilitate positive adaptation under conditions of risk. These include positive temperament or disposition, high level of intellectual functioning, self-efficacy, positive sense of self-worth, perception of personal competence, skills to solve problems, internal locus of control, good attributions of control, and a sense of optimism.

Resilience as a trait has also moved from research to a popular definition: “We’ve all witnessed women and men who, despite their losses, rise to this challenge and carry on. . . . One quality these people share is resilience—the ability to bounce back from hardship” (“Heart,” 2001, p. 1).

“The concern in treating or considering resilience as a trait is that it places blame on the [individual] for failing to overcome adversity or risk. It also raises questions about the usefulness of prevention efforts because individual trait-like characteristics may not be amenable to change” (Fergus & Zimmerman, 2005, p. 405).

From an Adlerian perspective, trait-based models attempt to understand individuals through a psychology of possession, that is, through identifying the traits they supposedly possess. Instead, according to Adler, “individual psychology is the psychology of use and emphasizes the creative appropriation and exploitation of all these [hereditary and environmental] influences” (Ansbacher & Ansbacher, 1964, p. 205).

Underlying a trait approach is the idea that people relate to the outside world in a manner predetermined by the trait. Underlying the Adlerian approach are the ideas that (a) heredity supplies certain dispositions, (b) environment provides the opportunity for interpretation of self, others and the world, and (c) those interpretations are used creatively to form an attitude toward
life—an individual lifestyle.

**Positive Adaptation.** Tedeschi and Kilmer (2005) acknowledge the variety of operational definitions, yet state that “many consider resilience to be a personal trait or attribute of an individual, rather than a dynamic developmental process reflecting positive adjustment despite adversity” (p. 3). Trait-based models of resilience, while helpful in looking backward at the culmination of what happened in childhood to produce those measureable traits, run the danger of assuming that traits are set. Adaptation and development, however, open the path to adult development during challenges in adulthood. Masten (2001) characterizes resilience as “good outcomes in spite of serious threats to adaptation or development” (p. 228).

Benard incorporates both capacity and process: “Resiliency is an innate capacity for self-correction and survival in the face of adversity. . . . An intrinsic survival motivation underlies the development of resilience. This is an interactive, ecological process of self-correction through ‘active, ongoing adaptation to environments’” (cited in Ryan and Hoover, 2005, p. 117).

**Resilience as Thriving**

Boss (2006), although she too summarizes research as emphasizing traits or personal assets, compensatory and protective factors, and developmental competence, adds that “across disciplines, it is now agreed that [being resilient] means more than coping or overcoming. Resiliency means *thriving* under adverse conditions—in other words, maintaining one’s psychic and emotional health and one’s spirit for living life with joy” (pp. 51-52).

**Resilience as regulation of emotion.** Davidson (2000, p.3) defines resilience as:

the maintenance of high levels of positive affect and well-being in the face of significant adversity. It is not that resilient individuals never experience negative affect, but rather that the negative affect does not persist. . . . [They] show rapid decrements in various
biological systems after exposure to a negative or stressful event.

As a neuroscientist, his focus has become emotional regulation.

**Resilience as the norm.** Viewing resilience from a developmental perspective cements the idea, which only recently entered the research literature, that resilience is normative, not exceptional.

Masten (2001) emphasizes the “ordinariness of the phenomena. Resilience appears to be a common phenomenon that results in most cases from the operation of basic human adaptational systems” (p. 227). Bonnano (2005) states that although resilience theorists “have typically viewed [resilience] either as an aberration resulting from extreme denial or as a sign of exceptional emotional strength. . . , resilience is typically the most common outcome following exposure to a potentially traumatic event” (p. 135).

**Resilience as adult developmental opportunity.** Armstrong, Birnie-Lefcovitch, and Ungar (2005) emphasize interaction and reciprocity during childhood among risk, protective factors, and human developmental processes “including the development of cognition, regulation of behavior, and interactions with caregivers and the environment” (p. 275). In finding the normative aspect of being resilient in the face of great difficulty and in viewing resilience as responding to developmental or adaptational challenges—as well as insisting on resilience as thriving—researchers also open the door to resilience as an adult developmental opportunity.

This view is in keeping with the way Bonnano (2005) distinguishes, based on others’ research, between recovery and resilience:

Recovery is defined by moderate to severe initial elevations in psychological symptoms that significantly disrupt normal functioning and that decline gradually over the course of many months before returning to pre-trauma levels. In contrast, resilience is
characterized by relatively mild and short-lived disruptions and a stable trajectory of healthy functioning across time...” (pp. 135-136).

Healthy functioning across time could well be a description of thriving and fits well with Adlerian psychology, in that “functioning” can stand for movement with direct actions to overcome and “healthy” can stand for social interest or cooperation.

**Resilience as psychological capacity.** Kelley (2005) states that Bonanno’s research suggests “an innate psychological immune capacity that, when unhampered, produces well-being and wisdom even during extremely aversive events and facilitates psychological healing from the inside out” (p. 265). He warns that current empirical approaches “will inevitably lead... to a proliferation of theories and models that promote a myriad of external sources and causes of resilience... [An approach] more likely to produce breakthroughs in understanding health, resilience, recovery, and dysfunction is one that focuses on the psychological principles of mind, consciousness, and thought that combine to create all human experience and behavior from the inside out” (p. 265). Kelley’s view underlines how encouraging resilience in lives that include dementia is a matter of the psychology of the people who are on a dementia journey.

**A New Construct of Resilience**

The question at hand, how to encourage resilience in lives that include dementia, therefore becomes a matter of strengthening the individual and systemic ability to thrive despite external challenge or internal risk. Adults, with their familial and other relationships, grow or they get stuck. Kelley (2005) calls on psychology for “programs that help people access their innate capacity for resilience and optimal function[ing]” (p. 265).

In a new construct, resilience is not so much about the ways a person can do things, that is, individual capacity and learned or invented skill. Resilience is not so much characteristics
people have, that is, traits that are outcomes of one’s genetic make-up and/or developmental history. Resilience is neither a pathway that creates capacity nor a prescription that can be followed to guarantee psychological survival with a difficult event or situation. Resilience is not the end-state of a journey. Resilience is thriving and maintaining courage.

**Resilience within the Adlerian Framework**

Resilience as adaptation matches well with the Adlerian view of lifelong striving to overcome perceived inferiority or actual disability. To Adler, a will or spirit to overcome is part of human nature and not a trait in the sense that some people have it and some do not.

Resilience is active behavior in the here and now: acting, thinking, feeling, or declining to act. This behavior in the present moment arises purposefully out of the meaning, within the situation, that a person makes of self, others, and the world. The wellsprings of thriving behaviors, according to Adler (Ansbacher & Ansbacher, 1964), are the courage to meet the tasks of life as one encounters them, as well as the willingness to risk failure and being imperfect.

In the Adlerian view, resilience is normative to human experience, being comprised of behaviors that compensate for inadequacy by engaging the will or spirit to overcome. Adler described the wellsprings to this thriving: “Whether the individual compensates for his [or her inferiority feeling or] disability or increases his [or her] inferiority feeling depends on the conclusion which each individual draws, on his [or her] courage and [his or her] social interest” (Ansbacher & Ansbacher, 1964, pp. 188-189). The conclusion or interpretation is the meaning that the person gives to life. The person’s movement makes the meaning clear.

Courage is required to choose resilient or compensating behavior. Resilient people, in the Adlerian view, revise the meanings they give their lives and the people in them if their current meanings do not foster balanced performance in the three tasks of life (work, love, and
Resilient people, in the Adlerian view, are active. According to Adler (1931a), they do not side-step or resist action. They do not declare themselves unable to solve their problem by showing a “hesitating attitude. . . in which [they] begin to evade and want to secure [themselves] against a solution of the necessary problem” (p. 161).

Despite their discouragement, some people find vehicles to compensate through a healthy cooperation that furthers their goal while enhancing social ends. Resilient people, with courage, take direct action.

**Behaviors: Resilient or Discouraged**

In Adlerian psychology, all behavior has a purpose. The purpose is guided by the person’s unique and unitary lifestyle. This includes the goal toward which he or she moves in striving to be safe, to belong, and to matter or be worthwhile.

A model of resilient behavior (see figure 2) includes three types, each with a concomitant discouraged behavior. In a simple description, a person copes or reacts, adapts relationships or withdraws, and grows or endlessly repeats the same behavior despite experience that the behavior is useless to meet one’s goal. The courage/discouragement model is represented as a coin, which has two sides. This is because, in a sense, a person cannot have a quarter is his or her pocket without having both a heads and a tail. It is normal to hold the whole coin. Each coin, each behavior opportunity, is potential. Which side lands up has to do with what people tell themselves: what they perceive, how they interpret, what beliefs generate the behavior.

In working with people and families on the dementia journey, it is useful to consider their behaviors through the courage/discouragement model. Often advice and counsel to people dealing with dementia are couched in lists and anecdotes rather than being described within a
contextual framework. The value of the framework is that people can generalize from situations and strike out in new directions in their behaviors. The list-and-anecdote approach provides assistance only if their situation matches the specific example.

The three behavioral challenges/opportunities of the dementia journey are to cope, to adapt, and to grow or transform. Instead of coping, discouraged people will react to stimuli. To cope is to behave in ways that encourage others or that directly solve problems of daily living.

Rather than adapt relationships to new circumstances, discouraged people typically will withdraw from relationships. Instead of growing, that is, developing new ways of responding to challenges, discouraged people can be stuck or endlessly repeat behaviors that do not work. Discouraged people often cling to mistaken beliefs about self, others, and the world that underpin their lifestyles. Those mistaken beliefs keep them in the same behaviors. The path to moving from discouragement to courage is to change the mistaken beliefs.

**Coping.** Coping behaviors are practical actions to produce different results. A person can advise another on ideas for coping. Support groups and the popular literature most often provide such advice.

Although not successfully coping may be the result of a lack of knowledge or skills, it can also be due to psychological impediments of safeguarding, mistaken beliefs, biased apperceptions, or a mistaken goal that is not in keeping with social interest, that is, absent cooperation. A person could have a great deal of knowledge, even skills, yet come up against psychological impediments. When this is the case, a support group alone will rarely suffice for the person to wholly change his or her way of coping.

Reactive behavior is discouraged behavior, within the lifestyle of the individual. There are four distinctive and mistaken desires in these behaviors, as first laid out by Dreikurs and
Soltz (1964) in working with children. “These were (a) to gain undue attention. . .; (2) to demonstrate power or defiance; (3) to seek revenge or retaliation; or (4) to give up in complete discouragement” (Terner & Pew, 1978, p. 156).

Bettner and Lew (1989) describe the alternative, constructive behaviors as the “Crucial C’s—being connected to others, having the capability to take care of oneself, knowing that one counts and is valued, and having courage” (p. 6).

Attention-seeking is a mistaken or reacting approach to meeting the underlying purpose of connecting. Power-seeking has the underlying purpose of feeling capable. The purpose of revenge is to count or matter. Giving up has the purpose of safeguarding, that is, avoiding defeat by not trying. Such misguided behaviors are “attempts to compensate for a feeling of inadequacy or insecurity indirectly, based on a mistaken ‘private logic’” (Adler, 1998a, p. 237).

**Adapting.** Adapting behaviors operate in the social realm. They are about doing things differently together. A person can tell someone relational options, but not provide the one right answer. The basis for adapting is cooperation. This means “we must work together to meet the demands of the situation” (Dreikurs & Soltz, 1964, p. 129).

Adler takes this point further: “Life presents only such problems as require the ability to cooperate for their solution” (Ansbacher & Ansbacher, 1964, p. 136). Discouraged behavior is withdrawing social interest. This might be simply withdrawal from relationship.

In Adler’s view, “discouraged people [attempt] to solve their life-problems without the use of cooperation or social interest” (Ansbacher & Ansbacher, 1964, p. 299). They operate on the vertical plane with others rather than the horizontal plane.

“The vertical movement of self-elevation, regardless of the heights it leads to, . . . can never bring lasting satisfaction and inner peace. There is a constant danger of falling and failing;
the gnawing feeling of real or possible inferiority is never eradicated” (Dreikurs, 1973, p. 41).

Most discouraged people are stuck because of the lifestyle they developed in childhood through their private logic. This childhood-based logic does not in adulthood contribute to the requirements, often social, of the situations that the adult encounters. According to Adler (1998b), if people have their courage when they have a feeling of inferiority in the face of those situations that they wish to improve, they set out to get rid of the feelings “by direct, realistic, and satisfactory means—that of improving the situation. No human being can bear a feeling of inferiority for long” (p. 40). Stress demands action.

However, a discouraged person typically cannot imagine that his or her efforts will improve the situation; yet the feelings of inferiority are unbearable. The answer he or she attempts to realize is to feel superior, a self-deception that deepens because the situation remains unaltered. “The discouraged person has the same goal as the person with courage: to triumph over the inferiority feeling and to be seen as successful and worthy of respect in the human world. However, he or she lacks the courage to operate on the useful side of life, in the fear of being exposed as deficient. The movement toward success is then deflected toward finding a place of personal superiority over others” (Griffith & Powers, 2007, p. 20).

**Aggressive discouragement.** Adler (Ansbacher & Ansbacher, 1964) also describes an aggressive form of safeguarding which has several subtle presentations. These may include depreciation—by holding the other up against an ideal—or by such utter solicitude of others as to insinuate their complete incapacity to care for themselves. A second aggressive stance is accusation, carried out by blaming someone else, finding another irresponsible, or holding the belief that another has deprived him or her of the supreme right to be the center of attention. Adler’s third aggressive stance is self-accusation and guilt, in which the other is prompted to
soothe or atone when the safeguarding individual makes self-accusations or uses suicidal threats to say how guilty he or she feels.

**Other aggressive antisocial behaviors.** Adler (1998a) points out particular forms of hostile behavior: vanity and ambition, playing God, jealousy, envy, greed, and hate. He also describes forms of hostile isolation: withdrawal, anxiety, timidity, and absence of social graces. In addition, he points out lesser expressions of reduced social interest: childish cheerfulness, chronic killjoy mood, use of clichés or vulgarity, eagerness to be the first to speak up, pedantry, prejudice, submissiveness, imperiousness, dependence on bad luck explanations, and religiosity in a sense that God “is concerned entirely with serving them” (p. 214).

**Growing.** Growing is to find a new understanding of self, others, or the world. A person (a) transforms the interpretations or meanings he or she derives from experience, (b) may take a new interpretation of the fictive goal, (c) finds the means to revise private logic, and (d) uncovers the hidden sources of courage that kept him or her from direct action to change self or situation.

Stein (n.d.) states that “Adler’s primary index for mental health is the person’s feeling of community and connectedness with all of life” (p. 1). Feeling secure comes from this sense of embeddedness. This “leads to an attitude of cooperative interdependency and a desire to contribute” (p. 1).

Oberst and Stewart (2003) summarize the evolution of Adlerian ideas about the innate human striving that underlies growth. Early in his conception of what motivates people, Adler focused on striving for superiority, an inborn trend towards growth, accomplishment, and mastering life’s challenges. Next, Adler emphasized striving for perfection, the desire to realize dreams, goals, and an idealized self-conception. Later, Adler described striving for completion, contribution, and belonging. “Individuals try to find a place among people. They try to answer
the question: ‘How can I fit in and also be all that I can be?’” (p. 22).

Growing is learning and acting to fit in and cooperate. Growing is being fully oneself and at the same time acting on a horizontal plane with others. Growing happens with courage, and it happens through encouragement of another person. Growing can proceed from expressing social interest toward the discouraged person.

**Encouragement through Emotion**

Ansbacher and Ansbacher (1964) report Adler’s definition of encouragement as “activating social interest” (p. 341). At its simplest, courage is interacting with others. At its simplest, encouragement of a person with dementia is being emotionally present for the interactions he or she offers.

“To encourage is to promote and activate the community feeling, that is, the sense of belonging, value, worthwhileness, and welcome in the human community” (Griffith & Powers, 2007, p. 20). To encourage a discouraged person is to express thoughts and feelings to help the person “become more active in the field of social usefulness” (Rom, as cited in Beames, 1992, p. 20).

Resilient people understand the role of emotions as a vehicle for both knowledge and action. In the Adlerian view, emotions “provide the fuel. . . for our actions, the driving force without which we would be impotent. They come into play whenever we decide to do something forcefully” (Dreikurs, 1967, p. 207).

Dreikurs emphasizes that emotions are about movement. “Our emotions are the steam which we give ourselves in order to fortify ourselves in the direction in which we want to move” (1972, p. 40). One can act, striving to overcome and incorporating the courage to fail, or one can display such evidences of discouragement as the safeguarding tendencies described previously.
“Emotion arises out of cognition and empowers behavior. Emotions, since they give rise to action, reveal the private logic, [and] provide an indication of the purpose for the behavior” (Beames, 1992, no page). Indeed, in Adlerian psychology, all behavior has a purpose. This is different from asserting that all behavior has a conscious plan and premeditated utility. However, behavior is not arrived at without purpose, albeit perhaps unconsciously. This is particularly significant to the understanding of those behaviors of a person with dementia that may seem random and without interpretative value.

A person who has courage discards maneuvers that have an intention to safeguard.

Courage is expressed in action to meet the tasks of life as they are encountered, despite the individual’s inability to predict the outcomes; . . .one does not acquire courage to meet danger. It is in meeting the danger, in daring to risk, that the individual acquires courage. (Beames, 1992, no page)

Actions that meet the danger and behaviors that dare to risk are the hallmarks of thriving.

**Approaches to Encouraging Dementia Resilience**

To encourage dementia resilience is to draw forth and to share cooperation. Becoming engaged in a cooperative relationship creates mutual courage. Encouraging dementia resilience appears in expressing social interest toward the person with dementia, caregivers, and family members.

**Encouraging through a Helping Relationship**

Courage arises when people experience another’s social interest directed toward them. Having someone join their efforts to one’s own is encouraging. This can happen within a therapeutic relationship, but any relationship can give rise to courage. While the descriptions below apply to psychotherapy, the concepts apply as well to any helping relationship with a
person on a dementia journey.

In fact, Adler’s description of the aim of psychotherapy can be edited to a prescription for encouragement. People “must be guided away from [themselves], toward productivity for others; [they] must be educated toward social interest; they must be led from . . . seclusion from the world, back to existence; they must be brought to the only correct insight: that [each] is as important for the community as anyone else; [each] must get to feel at home on this earth [despite their own or society’s dementia-related mistaken beliefs]” (Adler, 1928, as cited in Adler, 1932a, [footnote] p. 200).

**Therapy as encouragement.** The goal of therapy “is essentially to get the patient to recognize the mistake in [the] life style, the striving for a socially useless goal of superiority. . . and [to] increase the [person’s] ability to cooperate. This is a process of cognitive reorganization, of belated maturation” (Ansbacher & Ansbacher, 1979, p. 190).

Adler states that “psychotherapy is an exercise in cooperation and a test of cooperation. We can succeed only if we are genuinely interested in the other. We must be able to see with [clients’] eyes and hear with [their] ears. [Clients] must contribute [their] part to our common understanding. . . . We must cooperate with [them] in finding [their] mistakes, both for [their] own benefit and for the welfare of others” (Ansbacher & Ansbacher, 1964, p. 340).

Building up courage is the primary path of therapy, according to Adler (Ansbacher & Ansbacher, 1964), in that “we are always able to draw attention to errors only and never to innate defects, . . . to equality with others, and also to the generally low level of social interest” (p. 342). In therapy, the social interest of the client rises to meet the social interest of the therapist.

Jourard (1959) emphasizes the I-Thou nature of therapy: “No patient can be expected to drop all his [or her] defenses and reveal himself [or herself] except in the presence of someone
whom he [or she] believes is for him [or her], and not for a theory, dogma, or technique. . . .

Therapy proceeds through honest response to this very person by this very person” (p. 178).

Joining people on a dementia journey. The first requirement for joining is to accept the unique nature of each journey. Working with someone with dementia is always a matter of paying attention to this very person. The second requirement is to maintain an open attitude toward the new wholeness of the person with dementia. The third requirement is to recognize the ways that dementia isolates people on their journey. Therapy depends on an encouraging and discerning cooperation around coping, adapting, and growing, and it depends on breaking through the isolation to bring the client into a cooperative relationship.

Encouraging Resilience in the Person with Dementia

Kitwood (1997) simplifies the multiple complex definitions of dementia to two kinds of simultaneous change. The first is a progressive change of mental ability, in which he includes changes in memory, reasoning, and comprehension. The second is change in patterns of social relationships and interactions. He suggests that the frequent uses of stages of the disease, as in Reisburg and colleagues’ identification of “seven stages of ‘global deterioration’” (in Kitwood, p. 21), can lead to “neurological determinism” (Kitwood, p. 22).

In effect, if one characterizes the person through his or her deficiency, one will see the person only in neurological terms. Focusing on the neurological state of the person with dementia can come close to defining the person by his or her deficits. The result is to lose sight of the unique individual.

Dementia is a psychosocial condition, not just a neurological one. Citing Makin, Kitwood (1997) describes the social model of disability or disablement in which other people’s actions, attitudes, and neglect combine to “actively disempower those who have some kind of
‘difference’, overlooking their attempts at action and denying them a voice” (p. 46).

**Human needs.** Neurological determinism focuses attention on cure and prevention rather than what happens in the social and psychological present of the person with dementia. Kitwood (1997) contends that separation from relationships is what deprives the person with the disease of his or her personhood.

In counterpoint to deprivation of personhood, Kitwood and Bredin (as cited in Post, 2000) describe the ethic of dementia care as enhancing well-being. The details of the ethic match well with the Adlerian view of the needs that humans strive to fulfill:

1. To meet the human need to belong, enhance well-being by facilitating social confidence.
2. To meet the need to be safe, facilitate a basic trust or security in others and in the environment.
3. To meet the need to matter, facilitate personal worthiness and a sense of agency.

In a person with dementia, as with all people, these needs are met through social interaction. Kitwood’s research identifies 17 elements of malignant social psychology (1997). These can be understood in Adlerian terms as violations of needs that humans strive to fulfill. People with dementia have the same needs as other people. Dementia does not eliminate these basic aspects of being human. No matter the condition, loss of one faculty does not equal loss of humanity (J. M. Reardon, personal communication, October 14, 2009).

**Need to belong.** The Kitwood elements of malignant social psychology that violate the need to belong are (a) stigmatization, i.e., treating as an outcast or an object, (b) invalidation, i.e., not accepting their subjective reality, (c) banishment, i.e., excluding them, (d) ignoring, i.e., acting in their presence as if they are not there, and (e) mockery, i.e., humiliating them or making
jokes about their actions or words.

**Need to be safe.** The Kitwood elements of malignant social psychology that violate the need to be safe are (a) treachery, i.e., using deception to manipulate or distract, (b) intimidation, i.e., using threats that make them fearful, (c) outpacing, i.e., putting them under pressure to listen, speak, or do things more quickly than they can, (d) accusation, i.e., blaming when actions are caused by disability or inability to understand, and (e) disruption, i.e., disturbing their frame of reference or suddenly intruding on their conversation or action.

**Need to matter or be significant.** The Kitwood elements of malignant social psychology that violate the need to matter or be significant are (a) disempowerment, i.e., not letting them use the abilities they have, (b) infantilization, i.e., treating them as a young child, (c) labeling, i.e., treating them as if dementia were their basic identity, (d) objectification, i.e., identifying them through their bodily functions rather than their sentience, (e) imposition, i.e., compelling their actions while ignoring their desires or ability to choose, (f) withholding, i.e., denying attention or needs, and (g) disparagement, i.e., dispensing the message that they are useless or worthless.

**Social interest.** Meeting the needs of the person with dementia involves kindling social interest—joining as equal humans on the path of life. Their contribution is an amalgam of their will to be understood, which is an aspect of their courage, and their will to cooperate, which is their social interest. These combine with the caregiver’s or professional helper’s skills in interpreting the behaviors and language of a person with dementia—of this person with dementia.

**Assessment.** The targets for assessment of the person with dementia have less to do with neurological disability and more to do with cooperation, communication, relationship, and emotion. In addition, the person’s behaviors can evidence well-being, in terms of agency,
Emotional energy, social vigor, and creativity. Surely personhood is inherent in such assessment targets, even if identity is different than before.

**Cooperation.** Adler emphasizes continual assessment for cooperation. “Every interview should consider whether the patient is on the way to cooperation. Every gesture, every expression, everything [said or not said] is evidence thereof” (Ansbacher & Ansbacher, 1964, p. 344).

**Communication.** Assessment of communication style and capacity is crucial, as continued ability to communicate helps stave off frustration. All people who interact with the person with dementia must develop expertise at receiving and sending messages in new ways. The potential sources for communication deficit include such elements as (a) word substitution, (b) incomplete sentences, (c) repetition, (d) diminished vocabulary, (e) broken chain of logic, (f) difficulty set shifting, (g) inability to break ideas down or create abstractions, (h) pretending to understand, (i) distraction, and (j) inability to remember elements of long or compound sentences.

**Relationship.** Kitwood (1997) describes a short case that includes “disempowerment, intimidation, invalidation, banishment, objectification, imposition and withholding. . . . The malignancy tends to increase in proportion to three factors: fear, anonymity and the differential of power” (p. 48). Fear, anonymity, and power are all relational characteristics. In the therapeutic relationship, the therapist assesses their presence in the person with dementia in order to assess current relational positioning.

**Emotion.** W. A. Caron (personal communication, 2006) and Kitwood (1997) both emphasize the importance of emotions in the life of the person with dementia. Emotion is where the connection takes place for both care and therapy. Assessment identifies the emotions that are
available for making these connections. Emotions can often be uncovered in the behaviors of the person with dementia, the results of the behavior, and the purposes that are evident in the results of the behavior. Usually, the result of the behavior is its purpose.

**Well-being.** Kitwood and Bredin (as cited in Post, 2000) list indicators of well-being that are extant even in people with severe dementia. Assessing the presence and presentation of these indicators gives both a sense of the lifestyle of the person with dementia and a vehicle for building cooperation. Four types of movement are evident in Kitwood and Bredin’s twelve indicators of well-being:

1. Agency, that is, initiative and identity, comes out in behaviors of asserting will, demonstrating self-respect, and relieving stress or relaxing.

2. Emotional energy presents as showing pleasure, expressing a range of emotions, and displaying warmth and affection.

3. Social vigor appears as initiating social contact, showing acceptance of others with dementia, being helpful, and showing sensitivity to social forms such as smiling and taking or patting a hand.

4. Creativity surfaces as exhibiting humor, expressing self, and, in addition to Kitwood and Bredin’s list, playing, inventing, and exploring various relational media, traditional or not.

Assessment of well-being rises from the behaviors of the person with dementia rather than a neurological scale of disease or a production-related scale of disability.

**Meaning.** Confusion is a hallmark of dementia. This can arise from such factors as (a) reduced communication and reasoning skills, (b) misrecognition of people, places, and possibly of self in a mirror or in recent pictures, (c) inability to learn new things, and (d)
misinterpretations generated by new fears or out of the lifestyle. Meanings become mixed. Yet in some portion, the person’s lifestyle remains. His or her overriding goal remains as a true north toward which to strive. Lifestyle is understood from the metaphors and stories a person uses to describe (also, in narrative therapy terms, to construct) the meaning of behaviors, events, and relationships in their lives.

Relating to people with dementia comes through understanding their beliefs about self, others, and the world. Self-beliefs are under stress in dementia. In the early to mid-levels of progression, the experience of loss is formidable and coalesces around being safe, belonging, and being significant. Making sense may collapse, but making meaning remains a firm intent.

**Understanding meaning.** Understanding and honoring the communicative messages and purposes of behaviors help the person make meaning of self, life, and situations. “The mode of expression may be different from that of everyday speech; meaning may be conveyed in a concrete, metaphorical or allusive way” (Kitwood, 1997, p. 74). In narrative therapy terms, people continue throughout life to construct stories through “self-regulation, ways in which [they] observe and correct [them]selves, as normalizing practices of self in culture” (Brown & August-Scott, 2007, p. xi). People make their lives make sense by the stories they tell and, according to White and Epston (1990, p. 10, as cited in Brown & August-Scott, p. xii), “It is this storying that determines the meaning ascribed to experience.”

Adler used projective devices such as early recollections and dreams for vehicles to understand mistaken beliefs and the fictive goal. These as well as other devices are useful with the person with dementia as long as some verbal or creative-arts capacity remains.

**Recognizing identity as meaning.** The fictional goal in the lifestyle is, in essence, an answer to the question, “Who am I?” or more certainly, “Who will I be when I am perfected or
complete?”—in face of likely loss of the dream of perfection. As the ability to consciously regenerate the old identity fades, a new identity arises partially through the one formulated in the therapeutic relationship but most certainly through the relationships with the caregiver, family, caring professionals, and friends. Isolation, either physical or through lack of communication or emotional contact, prevents this reformulation.

**Viewing identity as a social construct.** When people encounter the new experience of a dementia journey, they attempt to make sense of it and to develop a meaning that is coherent with their lifestyle. Without attention to the uniqueness of their journey, they rely on society’s dominant assumptions and constructions about the meaning of dementia and the lack of social value in the dementia experience. Instead, when others focus on the meaning the person with dementia makes, within his or her lifestyle, fictive goal, and beliefs, they provide a reformulated or refreshed identity that the person may not be able to hold on his or her own.

In effect, as presented by Kitwood (1997), others hold the identity in place. The person with dementia interprets self through the behavior of others. As self becomes uncertain and the world becomes confusing to interpret, beliefs about others increase in importance for behavioral motivation. One way to support identity is to facilitate a way of life that includes a role for the person with dementia that others name and honor.

**Movement.** To be resilient, that is, to thrive, is to continue to take direct action to overcome the felt minus. The actions taken by the person with dementia are important because they point to the final goal, that element of lifestyle that is “abstract in its purpose of assuring superiority [and] fictional in its task of conquering all the difficulties of life” (Ansbacher & Ansbacher, 1964, p. 95). Observing actions and behaviors is the way to understand a person’s line of movement, especially when described in terms of agency, emotional energy, social vigor,
and creativity. Adler directs us to follow the movement, not so much what a person says as what he or she does.

New behaviors that are present in people with dementia are often difficult behaviors for others in their lives. Strategies to deal with these behaviors make up much of the content of caregiver psychoeducation, support group advice, and books or other media presentations about people with dementia. Cone (2004), for instance, lays out many interventions for dealing with such behaviors. Examples include catastrophic reactions, resisting care, dangerous moves that result in injury, complaining, attention seeking, manipulation and splitting, yelling and screaming, verbal aggression, agitation, assault, wandering, and problems with bathing, eating, and sleep. According to Cone, “three fourths of the people in retirement, assisted living, or long-term care facilities will exhibit problem behaviors at some time” (p. 155).

In the past, psychotropic medication, isolation, and restraints were frequently the responses of choice to deal with these behaviors. Now caregivers and professional helpers often attempt a behavioral intervention by modifying surroundings or their own behavior. This approach, called habilitation, “focuses on respecting the feelings of people with dementia and making the most of their remaining capacities, rather than trying to restore lost abilities (rehabilitation)—often in vain—or impose rigid standard for thoughts and behaviors” (Rabins, 2009, p. 64). Examples are accepting their reality, streamlining their space, and enriching their world through pleasurable activities, social contact, and physical activity. These items are done for the person with dementia, but do not eliminate the need to attend to aspects of resilience that are done with them or by them.

**Coping-reacting.** Jointly understanding the purposes of their behaviors helps people with dementia to cope instead of react. Behavior arises from purpose, based on convictions and
Encouraging Dementia Resilience

Biased apperceptions. This is as true for the person with dementia as it is for anyone else. To emphasize a critical point for the understanding of resilience in people with dementia, their behavior is purposeful but not necessarily on purpose, that is, not always consciously chosen. Even seemingly reactive behaviors have purpose. Even seemingly incomprehensible behaviors have purpose. Being with them in an encouraging way means striving to understand and respond to the purpose instead of reacting to the behavior.

Kitwood (1997) states that the painful aspects of the dementia experience belong to three domains: feelings, global states, and severe depletion or burn-out states. Feelings include fear, panic, grief, frustration, sadness, anxiety, and anger. Global states include terror, misery, rage, and chaos. Depletion includes despair, depression, vegetation, exhaustion, and apathy. Reacting to the behaviors that arise from these states increases the isolation and discouragement of the person with dementia. Given their research, the work of Kitwood and of Norton (2009) would support the contention that reacting to behavior instead of responding to purposes increases the progression of dementia symptoms.

Adapting-withdrawing. Helping people with dementia adapt instead of withdraw is a matter of responding to their social vigor and energy as well as initiating social interaction with them. Based on his and others’ observations and research, Kitwood (1997) maintains there are 12 types of positive interactions that will support the needs of people with dementia. These interactions relate to caring relationships, therapeutic relationships, and preserving the initiative of the person with dementia.

In terms of a relationship that is caring, he includes recognition, negotiation, collaboration, play, timalation (described as an interaction that is sensory, without conceptual content), celebration, and relaxation. In terms of a relationship that is therapeutic, he includes
validation, holding, and facilitation. In terms of the initiative of the person with dementia, he includes creation and giving. These interactions provide movement opportunities to create, to give, and to cooperate. They can be very encouraging to people with dementia and reduce tendencies toward early withdrawal from relationships and into the social isolation that follows.

Growing-endlessly repeating. Working therapeutically with the person with dementia to retrieve or reinvent personhood, by encouraging resilience, is where healing begins. “It is possible to learn from the behaviour of people who have dementia. . . . In the course of dementia a person will try to use whatever resources he or she still has available. . . [Any behavior may be] their last desperate bid to remain psychologically alive” (Kitwood, 1997, p. 75). The role of caregivers and professional helpers is to notice these behaviors and encourage continued efforts to produce them. To continue to express purpose is to grow and to thrive.

Courage. Depression, disinterest, and withdrawal are among signs of discouragement in a person with dementia, as are anger and hyperarousal. The progressive nature of the disease coupled with a sense of being useless can reduce initiative and interaction prior to reaching a neurological state necessitating such status. In other words, people with dementia are frequently discouraged.

Encouraging the person with dementia. The challenges of interacting with anyone who is discouraged may also appear in full force in the person with dementia. Courage arises through an emphasis on connection and emotion. Encouraging is allowing a person with dementia to contribute. Encouraging is joining their purposive efforts.

Encouragement as contributing rather than competing for perfection. Terner and Pew state:

To be human does not mean to be right, does not mean to be perfect. To be human
means to be useful, to make contributions—not for oneself, but for others—to take what
there is and to make the best of it. . . . We have to realize that we’re good enough as we
are; we never will be better, regardless of how much more we may know, how much
more skill we may acquire, how much status or money or what-have-you. If we can’t
make peace with ourselves as we are, we never will be able to make peace with
ourselves. This requires the courage to be imperfect; requires the realization that ‘I am
no angel, that I am no superhuman, that I make mistakes, that I have faults. But I am
pretty good because I don’t have to be better than others’—which is a tremendous relief. .
. . If we learn to function—to do our best regardless of what it is—out of the enjoyment
of functioning, we can grow just as well, even better than if we drove ourselves to be

People with dementia have the emotions and creativity to build relationships. Those who
interact with them can insist on characterization of errors not defects, equal value with others,
unique communication modes, and an increasing social interest.

Encouragement as joining. When interacting with a person with dementia, it is critical
to analyze words or actions for communication, behaviors for purposes, and emotions for
opportunities to connect. Adapting Dinkmeyer and Sperry’s (2000) approach to therapy, a
caregiver, family member, or helping professional must exhibit behaviors that take into account
such possible mechanisms for the behaviors of the person with dementia as:

1. fears of disapproval, being defective, or being exposed.

2. defenses of externalization and self-protection (to preserve self-esteem), cynicism (to
   escape responsibility), inadequacy (to refuse to try, thereby escape failure), or
   rebellion (to side-step ordinary rules of life).
3. avoidance of the real-life challenges to their private logic, patterns of striving, and discouragement. This can include developing blind spots, excessive self-control, arbitrary rightness, elusiveness and confusion, contrition and self-disparagement, or “suffering” as means of manipulation.

What is encouraging to people with dementia is joining them around their fears, defenses, and avoidance by responding to their purposes rather than reacting to their words or behaviors. This contention of purposive behavior is contrary to current views about dementia, remains to be tested, and will be rejected out of hand by many people. When people consider this point, it is easy for them to confuse purposive behavior (having a purpose) with intentional behavior (doing things on purpose).

However, since their behaviors have purpose deep into the progression of the disease, it is possible to continue to read purposes and have hunches about what lies beneath the behaviors. People with dementia are sensitive to emotions in a situation and to nonverbal cues. They will interpret subtle signs in others’ behaviors and words. Although they may not show evidence of seeing these signs, their own behaviors are the records of their responses.

**Encouraging Resilience in the Caregiver**

In 2008 (AA, 2009), almost 10 million Americans were unpaid dementia caregivers, each contributing an annual average of 863 hours in that care. Forty percent rate their emotional stress as high or very high. About one-third of family caregivers have symptoms of depression. Schulz, Belle, et al. (as cited in AA, 2009), report no reduction in stress after placement of the person in a nursing home. A popular book for caregivers captures in its title, *The 36-Hour Day*, the sense of unending responsibility that caregivers report.

Schulz, O’Brien, et al. (as cited in AA, 2009) report higher morbidity in caregivers of
people hospitalized for dementia than in caregivers of people hospitalized for other reasons. Covinsky et al. (as cited in AA, 2009) report that dementia caregivers were 31% more likely than other elder caregivers to have quit or cut back on paid work, even without behavioral symptoms in the person they cared for. With behavioral symptoms, they were 68% more likely to have reduced hours or quit work.

**Importance of caregiver resilience.** Caregiver resilience is a necessary support to good outcomes for people with dementia. Reason alone indicates that the caregiver is a critical link to quality of life for the person with dementia. Kitwood (1993, as cited in Norton et al., 2009) describes caregiving as an engagement that is both cooperative and reciprocal. Such relational characteristics depend on caregiver emotional availability, imagination, and empathy, as well as thinking that is flexible. A cooperative and reciprocal engagement in a relationship with a person with dementia is unlikely if a caregiver is discouraged, disheartened, or feeling overwhelmed. Pre-existing mental health issues can increase level of challenge to the caregiver.

Norton et al. (2009) highlight research findings that demonstrate successful outcomes for the person with dementia when caregivers use supporting rather than nonaccepting strategies, have higher commitment and good health, stimulate cognitive abilities of the person with dementia, and create positive interactions.

Gaugler, Kane, Kane, and Newcomer (2005a) report a complicated adaptation process in which caregivers who are confronted early in their caregiving careers with stresses like “wandering, exhibiting aggression, or acting in a socially inappropriate manner” (p. 107) are likely to place the person with dementia in institutional care sooner than other caregivers. Gaugler et al. (2005b) found that “as the functioning of the care recipient begins to deteriorate and unmet needs for . . . activity of daily living (ADL) care emerge, such as eating, bathing, or
toileting, the challenge” (p. 2103) to the caregiver increases. The result was more frequent nursing home placement and mortality of the person with dementia than when the caregiver reported fewer unmet ADL needs.

Norton et al. (2009) used interdependence theory and an investment model of commitment to form a research hypothesis that relationships between Alzheimer's caregivers and the person with dementia that were characterized as close would result in better cognitive and functional outcomes. They found that people with mild to moderate Alzheimer's who were in closer relationships with caregivers declined more slowly in cognition and functional capacity. “The effects . . . were on the same order of magnitude” (p. 6) as a meta-analysis of nine clinical trials of pharmacological treatment.

While additional research will attempt to untangle all possible embedded causal associations and to target interventions, the opening of this research frontier may be helpful to the people receiving care. Unfortunately, a by-product may be added stress on the caregiver to measure up to standards of closeness in addition to current standards of care.

Assessment. Except for neurological and occupational therapy assessment tools for the person with dementia, much of the assessment literature related to dementia focuses on the caregiver. Tremendous research energy and resource goes to this assessment task, often as a foundation to measuring the efficacy of interventions. Assessment research to measure caregiver well-being (or frequently, insufficiency or pathology) reveals the assumptions held in the mental health profession about the state in which caregivers are apt to be found, especially their high potential for depression and anxiety.

Assessment tools. Frequently, research and assessment tools mirror the predominant stress and burden approach to the caregiver role. At its heart, the problem with burden is that it
can call into play a model of victimization. “I am victim” does little to encourage the caregiver. In an unpublished review of assessment instruments to measure status of or change in dementia caregivers, Pinke (2008) reviewed 26 articles and found 54 caregiver assessment tools. These tools fell roughly within 11 categories, as matched to types of resilience:

Protective factors. Two articles describe their measures as resilience of protective factors.

- Protective factors (Baruth & Carroll, 2002) included adaptive personality, supportive environment, fewer stressors, and compensating experiences. Friborg, Hjemdal, Rosenvinge, and Martinussen (2003) measured adjustment and coherence. They also measured resilience in terms of coping behaviors and as a personality characteristic.

Traits.

- Caregiver traits: measures of angry temperament, health, learning style, self-esteem, and cognitive beliefs about helping.
- Psychological pathology: psychiatric diagnoses, most frequently depression and/or anxiety.
- Diagnostic symptoms/problems: symptoms of conditions such as depression, anxiety, somatization, grief, or bereavement; also, caregiver’s impressions of the memory and behavior symptoms of the person with dementia.
- Emotion: a wide range of approaches including positive and negative affect; a range from very happy to very unhappy; angry reactions (including variance across suppressed, expressed, and controlled); emotional stability or hardiness; and expressed emotion (criticism or emotional over-involvement).

Adaptation.
• Burden: Vitaliano, Russo, Young, Teri, and Maiuro (1991) characterize burden as a model of distress (both psychological and physical). Their burden formulation is the caregiver’s exposure to stressors, magnified by his or her vulnerability, and mediated by the caregiver’s psychological, coping, and social resources. According to Vitaliano et al., research suggests that gender, age, personality, and health problems may increase risk for burden, while social support, coping processes, and belief systems (as in outlook on life) may decrease risk.

• Coping included two main types: problem-solving (management of the source of stress) and emotion-focused (regulation of emotions). In the latter type, Aldwin, Shaefer, Coyne, and Lazarus (1980) included wishful thinking, growth, minimizing threat, seeking social support, blaming self, and mixed (both avoidant and help-seeking).

• Existential: overall satisfaction with life, manageability of life, and meaningfulness (as in clarity of goal or purpose), as well as ability to make sense of the situation.

• Relationship: collective efficacy of the family; categories of behaviorally-oriented and problem-solving communications between the person with dementia and the caregiver.

• Self-efficacy: the caregiver’s beliefs about ability and progress in responding to situations, obtaining help, solving problems, regulating emotions and upsetting thoughts, or protecting self-esteem.

• Social support: availability of and satisfaction with support from friends, family, neighbors, professionals, and clergy across different types of needs.

The selection design of articles for inclusion in the review does not address validity of
conclusions about frequency of utilization of approaches. However, burden and psychological pathology had the highest frequency in this group of articles.

Most importantly, measurement schemas are critical to social views of success/failure of dementia caregiving. Moreover, they form the basis of professional design and testing of interventions.

*Adlerian approach to assessment.* Protective factors- and trait-based measures rely on a psychology of possession, not the Adlerian psychology of use, so are of minimal value to assessment of encouraging dementia resilience. Instead, assessment can include caregivers’ “opinion of [their] goal of superiority, the strength of their inferiority feeling, the degree of [their] social interest, and the fact that the whole individual cannot be torn from [the] context with . . . society” (Ansbacher & Ansbacher, 1964, p. 327).

Relative to the cope-adapt-grow model of resilience, the three measures of relationship, social support, and coping as problem-solving fit as coping resilience behaviors. Burden, existential, self-efficacy, and coping as emotion regulation measures may best fit assessment strategies that use Adlerian resilience approaches.

An Adlerian resilience assessment looks to identify mistaken beliefs about self, others, and the world that impact a caregiver meeting his or her needs to be safe, belong, and matter within the caregiver role. In other words, look for challenges to lifestyle instead of to traits, coping activities, and social supports. Look for a changed sense of the relationship, including self-identity in the new relationship and dealing with unresolved elements of the old relationship. Look for private logic that stands in the way of finding new meaning that provides for growth.

**Meaning.** A downside of the term burden is that it has moved, perhaps through careless professional jargon, from a specific meaning in academic research into general use in society and
now influences the social norms around caregiving. In this vein, Roach (n.d.) states that “the meaning one places on a task determines how burdensome the task is” (p. 4).

Burden denotes something to be carried, but connotes something onerous or imposed. Nothing can be clearer than the words of a dementia caregiver about the struggle in our society to find meaning in caregiving:

While the tasks are difficult for those facing this illness, the constant imprint of this care as burden serves little purpose except to wear down the caregiver. The use of the phrase [the burden of caregiving] demeans the act itself and it demeans the caregiver by default. How does one provide a loving and life affirming environment for someone going through this disease when everyone characterizes your resolve in terms of drudgery?

(Murphy, 2002, p. 1)

This same caregiver points out that talking about how hard it must be to watch people with dementia lose their dignity ignores the reality that dignity comes from the observer, not the person being observed. She also rebukes people who would suggest that visiting someone in the nursing home is worthless when the person with dementia does not recognize people anymore and reminds them that, “as long as we know who they are, that is all that matters” (p. 2).

Because of their emotional investment in their own learning, caregivers make excellent teachers and advocates.

Existential meaning. In their research, Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991) found the primary existential themes expressed by caregivers to be loss and powerlessness; acknowledging present loss; acknowledging powerlessness; the role of values, choice, and provisional and ultimate meaning; and making personal choices. Caregiving is a personal responsibility that the caregiver undertakes, in the Adlerian term, through his or her
individual lifestyle and degree of social interest. There are no ready prescriptions for what caregiving should mean or for an ideal meaning that fosters resilience, but creating meaning is critical to caregiver endurance.

Farran et al. (1991) describe four assumptions about meaning that have been postulated by Frankl and by Missinne and Willeke-Kay and can be applied to caregivers. First, people create meaning through their choices. Second, values are the foundation for meaning. Frankl identified values as of three types: creative, experiential, and life belief. Third, caregivers hold responsibility over how to carry out the role by accepting the choice of being caregiver. Fourth, both provisional and ultimate meaning exist. In other words, meaning can be found in day-to-day tasks as well as by embracing spiritual beliefs.

**Sense of coherence.** Antonovsky (as cited in Almedon, 2005) postulates a sense of coherence that is composed of (a) comprehensibility, can the person make sense of the challenge; (b) manageability, does the person perceive the resources are available to meet inordinate challenges; and (c) meaningfulness, does the person feel the challenges faced are worth the price of engagement.

**Dementia uncertainties.** Meaning can be difficult to pin down because the dementia experience provides uncertainty (a) about the ways the person with dementia is the same and the ways he or she is different from before, (b) about how rapidly additional changes will occur, (c) about necessary and optional role changes for the caregiver, (d) about the utility and meaning of relationships, and (e) about the roles the person with dementia can play in decisions about his or her own life and within the family system.

**Alternative cultures of dementia care.** Which of two cultures of care, as Kitwood (1997) describes them, a caregiver is more comfortable in will guide the meaning he or she makes of
dementia caregiving. Kitwood describes the old view of what caring entails as “concerned primarily with such matters as providing a safe environment, meeting basic needs, . . . and giving physical care in a competent way” (p.136). He describes the new culture as “concerned primarily with the maintenance and enhancement of personhood. . . . [The old-culture types of caring] are all essential, but only part of the care of the whole person” (p. 136). Post (2000) describes how old “culture’s criteria of rationality and productivity blind us to other ways of thinking about the meaning of our humanity and the nature of humane care” (p. 93). Broader cultural and social beliefs will also influence the meaning the caregiver takes from the dementia journey.

**Common themes about the caregiving experience.** Mittelman, Epstein, and Pierzchala (2003) describe a diversity of caregiving experiences, although common themes emerge. “Most caregivers are motivated by feelings of love and attachment, feel that they have grown as human beings, find value in the experience, and take pride in providing care and comfort” (p. 131). “Despite the fact that dementia is known to be progressive, almost all caregivers will suffer emotionally when they are confronted with evidence of the illness progressing and may temporarily lose their sense of equilibrium” (p. 130). Potentially, what happens is that a caregiver works hard to overcome a certain set of difficulties, relaxes into “oh, I can do this,” and then sees things change in ways that make clear the uncontrollability of the disease.

According to Mittelman et al. (2003), symptoms in the person with dementia that have symbolic meaning (loss of being recognized) or practical impact (inability of person with dementia to sleep through the night) may overwhelm the caregiver.

**Ambiguous loss.** In her resilience work, Boss focuses on the human experience of loss of a particular kind. In 1999, she described ambiguous loss as someone experiencing another
person’s absence or presence as not absolute, that is, not conclusive or certain. According to Boss (as cited in Abrams, 2001), an ambiguous loss is one that is incomplete or uncertain, and progressive dementia is complicated by the ambiguity of the loss because some of the former self is still present and because insight and capacity can vary from day to day.

Present psychologically but not here physically. Examples of people who “are not here but are psychologically here” include: (a) the 9/11 missing, (b) a divorced non-custodial parent, (c) a person missing in wartime action (d) someone in prison, (d) an abducted child, (e) the birth parent of an adopted person, and (f) the child released for adoption.

Present physically but not psychologically here. People who “are physically here but not fully here” include (a) a person with dementia, (b) a family member with substance abuse, (c) a workaholic or other parent primarily engaged outside the family, and (d) a person with brain damage induced by trauma or stroke.

For the family and caregiver, the person with dementia is physically present but not cognitively and/or communicatively present as before. Abrams (2001) describes the challenge as confronting the change by holding some meaning from the past while letting go of what is not present. To Boss, this is validating the loss but honoring the resiliency. False, end-of-relationship, end-of-my-life closure is unhealthy when the reality is different than complete loss. Trying to deny ambiguity (grieve your loss now) or close it (just do not think of him as your husband any more) would be equally confusing approaches to take.

Boss (2006) emphasizes how:

even without death, the people we care about disappear physically or fade away psychologically. . . . This ambiguity between absence and presence creates a unique kind of loss that has both psychological and physical qualities. . . . The premise is that
ambiguity coupled with loss creates a powerful barrier to coping and grieving and leads
to symptoms such as depression and relational conflict that erode human relationships (p. 1)

**Ambiguous difference.** The difficulty with Boss’s model of ambiguous loss is that it can lead to either-or thinking about the ways the person with dementia is “here” or “not here.”

Adlerian theory emphasizes instead the idea of “both-and;” the person is both here and not here, without making specific distinctions about what is physical and what is mental. In a way, either-or thinking promotes ambiguity while both-and promotes clarity (J. M. Reardon, personal communication, October 14, 2009).

In keeping with Adler’s “anything could also be different,” it also is possible to move from “loss” paradigm to “different” paradigm. When someone has dementia, they are different in how we experience them, different in their behaviors, different in their communicative and cognitive skills, but at the emotional core, still the living person—changed by his or her experience of loss, changed in our perceptions, but still there.

There is ambiguity, and there is much to be understood and applied from the ambiguous loss model. However, the concept of “loss” needs modulation to “new.” Ambiguous loss represents an attempt to hold onto the old while accommodating the new. “Ambiguous difference” characterizes the changes, be they observed, anticipated, or unknown. Instead of merely fostering an understanding of ambiguous loss, we must find ways to help people come to grips with the ambiguous differences in the dementia experience.

**Meaning as making sense.** Boss (2006) describes how critical meaning is to navigating an ambiguous loss:

Meaning, . . [is] being able to make sense of an event or situation. It means that one can
eventually find some logic, coherence, or rational reasoning about what has happened.

Human experience is meaningful when it is comprehensible to those who are having the experience. . . . Without meaning, people cannot really know what the problem is. Without that knowledge, there is no cognition; without cognition, they can’t cope and make decisions to move forward. (p. 74)

An Adlerian approach does not contemplate people being without meaning. Instead, the focus is on whether the meaning comes from mistaken beliefs. People will make meaning even if the meaning is not helpful to them.

**Movement.** Caregivers exhibit the same behavioral variation in movement as other people do, including direct actions to improve the situation as well as safeguarding and hesitation in face of a challenge to their belief in their ability to rise above the feeling of inferiority. They will not typically move forward when the problem is that they are discouraged. In addition to the psychological challenges that all people face are those challenges encountered in giving care to someone with progressive decline of capabilities across many domains. The nature of the caregiving challenge is varied and individuated per (a) the person with dementia, (b) caregiver attributes and development, (c) nature and history of the relationship between the person with dementia and the caregiver, (d) the family setting of both, (e) other supports, and (f) financial issues.

Many programmatic attempts to assist the caregiver focus on psychoeducation about the disease and coaching about coping with the safety of the person with dementia, with his or her activities of daily living, and with decisions about place of residence. Support groups are often caregiver-led efforts to band together for emotional support and to pass on tips for coping with activities of daily living (ADL).
There may exist psychological impediments to coping, adapting, or growing. If unresolved, these can leave caregivers to fend off “you should” prescriptions of decisions they “must” make and actions they “must” take. This makes the caregiver situation, despite programs intended to assist, more difficult because “shoulds” bring with them the specters of shame and guilt. These types of discouragement cannot be reached through more coping advice, but require caregiver growth.

**Coping-reacting.** “Caregiver . . . behaviors [are] categorized by Pearlin, Turner and Semple (1989): (1) prevention of stressful situations, (2) management of stressful situations, (3) management of meaning of stressful situations, and (4) management of internal symptoms of stress. . . . It is the flexibility and range of the coping repertoire that is important” (Caron, 1991, p. 34). A great deal of the coping challenge arises from aspects of the dementia journey.

**Nature of dementia illnesses.** Because dementia is a chronic disease that can be progressive at a slow rate, caregiving responsibilities can deepen in difficulty and extend over many years. Co-morbidities in health concerns are frequent. In addition, there are great variation and unpredictability for the course and combination of symptom, behavior, and capability changes in the person with dementia.

**Changed modes of interaction.** Due to changes in the person with dementia, new interactions will result in new activities and approaches entering the caregiver’s roles. These changes include losses or changes in (a) memory, (b) communication and thinking skills, and (c) executive function, i.e., ability of the person with dementia to “achieve [his or her] goals in daily life, such as initiating and stopping actions, planning, anticipating outcomes and adapting to changing situations” (Sabia et al., as cited in Tufts University, 2009). The person with dementia may also change in affect and behaviors. In addition, the person may lose his or her former
societal identity derived from work or other significant roles.

Financial issues. Financial responsibilities that were either shared in the past or may not have included the caregiver become lodged with the caregiver. The person with dementia may be unable to manage money or financial affairs. A shortage of resources often complicates the situation as the person with dementia is no longer able to work, especially when the caregiver needs to reduce working hours or eliminate outside work responsibilities altogether. In addition, the specter of long-term institutional care creates another realm of complicated learning for the caregiver—learning that extends beyond finances into legal matters.

Direct caregiver impacts. Caregivers may struggle with physical or mental health, exhaustion, and an expanding physical care workload as capacity of the person with dementia for ADL and personal care declines.

Adapting-withdrawing. Other aspects of the dementia journey require the adaptation of relationships.

Changed relationships. The person with dementia will no doubt experience as well as need different interactions and roles with the caregiver, other family members, co-workers, and friends or neighbors. The caregiver is often in charge of steering those changes. Caregivers often struggle with their own changing roles and boundaries and with isolation. The person with dementia may be unable or unwilling to cooperate and may resist care.

Safety of person with dementia. At some point in the progression of the disease, the caregiver will begin to take responsibility for safety. This requires adapting the relationship and can include assessing risk, taking protective action, assuring medical compliance, and responding to the impacts on the person with dementia as well as the caregiver’s own life. Increasingly, care for the person with dementia extends to round-the-clock monitoring and interventions.
Decision-making. Dementia caregiving includes (a) a growing need to make normal life decisions for another, (b) uncertainties about need for placement outside the home, and (c) ethical dilemmas. New or exacerbated family conflicts may arise concerning who makes what decisions.

Growing-endlessly repeating. Elements of the caregiver’s lifestyle may interfere with growth in meeting the challenges of the dementia journey. Emotionally, the caregiver may be dealing with feelings of (a) ambivalence, (b) indecisiveness, (c) wanting certainty, (d) resisting change, (e) being upset by seemingly incomprehensible behaviors, (f) loyalty intermingled with shame, (g) guilt, (h) having been betrayed, (i) mental exhaustion, (j) hopelessness and depression, (k) grief from ambiguous loss, and (l) meaninglessness. Even a previously-secure identity may weaken as energy or courage dwindles to meet the caregiver’s own needs to belong, matter, and be safe.

Courage. “There is. . . a vast difference between a tragedy, in which persons are actively involved and morally committed, and a blind and hopeless submission to fate” (Kitwood, 2008, p. 69). An attitude of hopeless submission to the fate of caregiving can be difficult for a weary caregiver to resist, especially since physical and psychic energies are necessary to fulfill the repeated tasks the caregiver undertakes.

Encouraging the dementia caregiver. To encourage the caregiver on coping tasks, bibliotherapy and support or psychoeducation groups are all useful approaches. In addition, development of problem-solving skills and attention to emotions and beliefs that interfere with daily coping are good strategies. Helping caregivers identify encouraging people and limit contact with people who discourage them is also useful. Focus caregiver attention back on his or her needs in order to have the endurance to cope.
To encourage the caregiver on adapting the relationship with the person with dementia, help him or her formulate the ambiguous and new nature of the relationship and to accept the ambivalence that may occur. Coach on how to interpret communication from and initiate communication with the person with dementia. Frequently, this will entail direct work with them together as the professional helper identifies communications modes of the person with dementia and coaches the caregiver on how to maintain communication.

It is useful to instill a sense that the person with dementia is acting as a care partner, not just a receiver of care, as he or she is no doubt working hard within his or her new capacities to make everything normal and routine. Unresolved issues from the previous relationship may be elements of the care relationship, and mistaken beliefs about self and about the person with dementia may be limiting success in adaptation.

To encourage caregiver growth, one must help him or her identify places where endlessly repeating the same behaviors is not making a difference. Proceed with as much lifestyle analysis and modification as is appropriate to balance the caregiver’s energy and needs. Uncovering and revising mistaken beliefs can release an abundance of courage and new found energy.

**Encouraging Resilience in the Caregiver-Care Partner Dyad**

In addition to the person with dementia and the caregiver, there also exists the relationship. This can be a couple in a committed relationship, in or out of marriage. It can be a non-intimate pair, such as parent-child, siblings, or non-related pair. There can also be two people sharing the caregiving role. For instance, an adult child might be supporting a parent who is caring for a spouse or partner. While this may create elements of triangulation, frequently the child takes responsibility for caregiving, with or without acknowledging it to the caregiver-parent.
Assessment—images of health. Many relational features can be assessed. However, the following five domains are solid indicators of health in the care relationship. The descriptions that follow are written for a committed couple. A different composition of the relationship may change how these look in practice.

The basis for the assessment is those aspects of a relationship where a dementia couple is most likely to be having difficulties or where a professional helper’s ethical concerns for quality of care or quality of life are likely to prompt intervention. The images of health in the relationship would change toward the end of the progression of dementia, with more attention paid to individual mental health than the health of the relationship. The five domains included below are courage, relational behaviors, communication, health care, and caregiver balance.

Individual and couple are resilient and show courage. People in relationship ideally have the ability, based on their resilience, to encourage each other (a) by coping together to get daily issues under satisfactory control, (b) by adapting their relationship as needed, and (c) by transforming their understandings of self, others, and the world as their individual development has an impact on their relationship. Gradations in health are described below in terms of an image of health in the courage domain and two examples each of a less and least healthy presentation:

Resilient. In a fully-functioning couple, the ideal image of health would be mutually encouraging behaviors and a courage that resides in them not just as individuals but in the workings and rules of their relationship. If both can find resilience, they are regularly encouraging each other with their behaviors. Their relationship thrives despite challenges. If only one is resilient, he or she demonstrates skills and knowledge to encourage the other partner. The care partner’s reasoning and communication capacities, due to the stage of the disease, will
affect the ability to understand resilience and apply to his or her own behaviors.

In the pre-diagnosis phase, first of seven phases outlined by Caron, Pattee, and Otteson (2000), care partners will have ability to participate in finding resilience if dealing with other therapeutic issues opens them to the possibility. In the diagnosis (second of seven) and role-changing phases (third of seven), care partners may still have the understanding to be able to encourage the caregiver. In the chronic care phase (fourth of seven), the care partner may be unable to respond to the intellectual challenge of initiating, but he or she will still be responding from an emotional base to the other’s encouragement.

**Less resilient, type 1.** Neither person shows resilience, but at least one has identified that the interaction of their discouraged behaviors is having an impact on the other. They may report failed attempts to interact differently or some successes without ability to generalize to other situations.

**Least resilient, type 1.** Neither person shows resilience, that is, both fall back on reacting, withdrawing, endlessly repeating behaviors rather than coping, adapting, and transforming behaviors. The result is to discourage each other.

**Less resilient, type 2.** Resilient partner feels some success in using behaviors that encourage the other and is applying resilience to other parts of his or her life, so has a sense of the efficacy that may be possible.

**Least resilient, type 2.** Partner who is resilient in other tasks of life has accepted the medical-model belief that nothing can change about difficult dementia behaviors except to medicate.

**Relational behaviors demonstrate working together.** As roles and boundaries change and what worked as a couple in the past no longer does, anger behaviors may increase and
ENCOURAGING DEMENTIA RESILIENCE

interfere with the necessary role changes. Gradations in health are described below in terms of an image of health in the relationship domain and two examples each of a less and least healthy presentation:

**Resilient.** Couple demonstrates role and interaction changes that support cooperation, reasonable self-reliance, contribution, and determination to try. Behaviors are aligned with each other’s purposes entailed in “I am connected,” “I am capable,” “I count,” and “I have courage” (Bettner & Lew, 1989).

**Less resilient, type 1.** The caregiver recognizes a need to change his or her interactions with the care partner, but is uncertain how to proceed, unskilled in interacting differently, or so bound in his or her own discouragement to be hard-pressed to try.

**Least resilient, type 1.** Individual or couple demonstrate mistaken goals of attention, power, revenge, or avoidance. These lead to behaviors which further discourage themselves and each other.

**Less resilient, type 2.** Caregiver is so bound in his or her own discouragement that he or she cannot imagine that there is another way to interact.

**Least resilient, type 2.** Caregiver is clinically depressed. Care partner is angry much of the time or more withdrawn than the stage of the disease would predict.

**Communication works to attainable level.** Communication is a challenge in any relationship that includes dementia. Language abilities deteriorate (in different ways with different variations of different diseases) and, even when verbalizing language skill seems extant, underlying reasoning deficits make reception of messages difficult for the care partner. The image of healthy conflict resolution in a couple with dementia-based communication challenges is dependent on their getting communication avenues re-established. Gradations in health are
described below in terms of an image of health in the communication domain and two examples each of a less and least healthy presentation:

**Resilient.** Caregiver knows how to watch for communication needs and successes, has a varied repertoire of things to try, has the courage to try (and fail sometimes), and is effective at communicating through emotional connection and perhaps through visual or sensory, non-language cues. Care partner evidences a desire to connect

**Less resilient, type 1.** Care partner’s capacity to communicate in some ways and his or her will to communicate are evident, but caregiver is not seeing it.

**Least resilient, type 1.** Care partner appears to lack the capacity to communicate, either due to damage to pertinent parts of the language-producing and –processing parts of the brain or due to reasoning deficits. Memory lapse may affect length of sentences that can be processed. Little evidence of caregiver attempt to modify his or her use of language. Caregiver may have, in effect, given up trying to communicate.

**Less resilient, type 2.** Caregiver is stuck at earlier stage of care partner capacity and keeps endlessly repeating what worked before, building frustration and stress. His or her energy goes into dealing with stress instead of finding useful coping mechanisms built on what care partner can still do.

**Least resilient, type 2.** Stress and frustration lead caregiver to acting-out behaviors that do not work to communicate her messages to his or her care partner.

**Roles and boundaries in health care situations support medical and mental health.** Images of couple health are complicated by the necessary changes of roles and boundaries in matters of the care partner’s health care. Relationships with health professionals need to change over time, and it can be difficult for professionals and the couple to make room for the
adaptation. Gradations in health are described below in terms of an image of health in the health care domain and two examples each of a less and least healthy presentation:

**Resilient.** The couple and health care providers have agreed on who makes what decisions and what the process will be to change this agreement. Caregiver understands value of health care provider’s objective view of care partner ability to participate in decisions. When care partner is not able to participate in decisions, caregiver assesses options from perspective of what care partner’s view of quality of life is rather than caregiver’s own view. Caregiver understands in later stages of disease that care partner can be happy with what caregiver would feel is a diminished quality of life.

**Less resilient, type 1.** Care partner allows caregiver participation in meetings and relationships; catch-as-can rather than deliberate approach to care partner involvement in decision-making.

**Least resilient, type 1.** Care partner shows evidence of suspicion about caregiver’s wish to participate in medical consultations and/or have a relationship with other professional helpers. Alternately, care partner denies need for more medical or mental health care when need is clear.

**Less resilient, type 2.** Who participates in each decision is handled on a case-by-case basis, resulting in continual conflict and stress between the caregiver and care partner. Care professional does not intervene. Caregiver wants a different approach because the frustration is showing as ambivalence: “I care about the decisions, but I care more about stopping the battles with my loved one” versus “I must be responsible for critical decisions if my care partner cannot be.”

**Least resilient, type 2.** Caregiver’s need to control all details or his or her fusion with care partner interferes with care partner’s rights to make or participate in health decisions to the
extent that his or her capacity allows.

**Mix of interdependent, dependent, and independent interactions supports balanced quality of life.** Quality of life (QOL), a most individual of judgments, is important to maintain for both care partner and caregiver. The key is to balance what is acceptable with what is possible, being ever alert to finding new possibilities for quality of life for each.

Thirteen items can be part of a QOL assessment: “Physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, and life as a whole” (Karlawish et al., 2003, p. 1392).

Gradations in health are described below in terms of an image of health in the balanced quality of life domain and two examples each of a less and least healthy presentation:

*Resilient.* Caregiver is thriving on the fourth and/or fifth tasks of life (relationship with self and spirituality) as a means for counterbalance beyond just adding activities in tasks one to three (work, love, social). If relationship prior to dementia was difficult, caregiver may move toward motivation out of social interest rather than out of loyalty to the couple’s former relationship.

Caregiver and care partner have an agreed care plan that provides for caregiver respite, caregiver life tasks beyond caregiving, care partner safety, and care partner comfort with living arrangements (if not immediately, then once the change is being experienced). Caregiver has knowledge and skills for dealing with care partner discomfort when it arises. Approach is in place for how to change the plan as care needs change, including caregiver satisfaction that when more care is needed, he or she has a qualified and in-place set of options available. Major changes (like placement in long-term care) are made early enough that care partner still has skills needed to make the transition emotionally.
Less resilient, type 1. Caregiver is hanging onto at least one other task of life in an attempt to find a counterbalance. Has some awareness that caregiving could be a developmental task of life rather than just a burden to be carried.

Least resilient, type 1. Care partner refuses any care but from caregiver and makes such a fuss that caregiver tries to accede. Caregiver does not have sufficient independent interactions with other people or activities outside the dementia realm to generate energy and courage for this part of his or her life. Caregiver has concluded caregiving is his or her identity.

Less resilient, type 2. Family members or alternative care providers needed for a care plan discount the knowledge of the caregiver about the care partner’s situation, the difficulty of caregiving responsibilities, or their own capacity to help. This can be to the point that getting them involved is such an emotional roller-coaster for the couple that the caregiver does not have the energy to try to get a plan together.

Least resilient, type 2. Caregiver is stuck in thinking that he or she holds the entire responsibility for providing care and ensuring the precise approach to care that he or she would take. Caregiver shows little evidence of willingness to explore options beyond just doing what he or she is already struggling to do: “Okay, now I can do this, so everything will be okay” is discounting the progressive nature of the disease.

Meaning. A primary challenge to meaning in the relationship is the necessary changes in roles as the dementia progresses. The members of the dyad attempt to understand the new relationship versus the old one. Roles shift, and meanings in a relationship play out through the roles the parties to the relationship adopt. Sometimes there is an assumption that the relationship is over and must change to parent-child as the person with dementia is infantilized. Yet a variety of additional roles are possible. Examples of new views of a caregiver’s role are (a) parent or
teacher (frequently chosen by women), (b) personal or resource manager (frequently chosen by men), (c) partner, (d) two-way interpreter (the world to the person with dementia as well as the person with dementia to the world), (e) co-creator, (f) pathfinder, and (g) facilitator or expeditor. Each of these roles carries certain moral values that must match the caregiver and care partner values.

In addition, each caregiver role emphasizes different aspects of the dementia patient, respectively: (a) child or student, (b) subordinate, client, customer, or contractor, (c) partner, (d) a person with reduced insight and/or communication skills, (e) co-creator, (f) scout, and (g) a person of will but not agency. Ambiguity of roles can lead to caregiver impatience, family conflict, or dementia patient anxiety, aggression, agitation, or apathy.

Despite chosen role changes, continued interactions on an emotional level build new and strong meanings around the changed roles for both the caregiver and the care partner.

**Movement.** Each of these areas of intimacy calls forth behaviors from both members of the dyad. As the journey proceeds, relational behaviors shift from predominantly talk to include more emphasis on touch, closeness, listening together, and observing together. Other behaviors are added, such as singing, dancing, or a broad range of other possibilities for active mutual behaviors. As care partner ability to initiate declines, the caregiver increases alertness to signs of intention from him or her. The caregiver may need to firmly but gently direct or guide desired behaviors.

**Responses to mistaken goals of behavior.** Figure 3, Dance of Discouragement/Encouragement, provides a detailed explanation and examples of how to change interactions between the care partner and caregiver. The “Dance” is based on the work of Bettner and Lew (1989), who cite Adler for recognizing that a “combination of needing others, being needed by
others, and needing to be self-sufficient are the basic desires common to all people” (p. 6). They “call these necessities. . . the Crucial C’s—being connected to others, having the capability to take care of oneself, knowing that one counts and is valued, and having courage”(p. 6). The Crucial C’s have roots through many Adlerians and back to Dreikurs and Soltz (1964). In the Adlerian literature, the model of the Crucial C’s is most frequently used to work with children’s misbehavior, yet the basic motivations also underlie adult lives. People with dementia, many of whom experience disinhibition, can demonstrate pronounced aspects of discouraged behaviors when their sense of self becomes less certain under their changed circumstances.

Applied to the dementia journey, the “Dance” lays out (a) typical behavior of a care partner or others who are on the dementia journey; (b) typical, impulsive reaction of someone interacting with the care partner; (c) reaction of the care partner to the reaction of the caregiver, (d) alternative, encouraging behavior of caregiver, and (e) how that behavior meets the underlying purpose of the care partner’s initial, mistaken behavior.

There are four discouraging cycles and for each a concomitant encouraging cycle:

1. Instead of reacting to a mistaken goal of seeking attention, the caregiver responds with encouraging behavior that meets the care partner’s underlying purpose: to connect.

2. Instead of reacting to power, caregiver responds with encouragement so the care partner feels capable.

3. Instead of reacting to revenge, the caregiver responds with encouragement so the care partner feels that he or she counts.

4. Instead of reacting to the care partner’s avoidance of initiating or participating, the caregiver responds to encourage him or her.
The key to identifying the mistaken goal is for the caregiver to check his or her own reactions to the behavior of the person with dementia. If the caregiver feels irritated or annoyed, the partner is seeking attention because of a need to connect. If the caregiver feels angry or challenged, the partner is seeking power because of a need to feel capable. If the caregiver feels hurt, the partner is seeking revenge because of a need to count or matter. If the caregiver feels despair or hopelessness, the partner is avoiding because of a lack of courage.

**Resilience and areas of intimacy.** Another way of conceptualizing couple’s movement is through Fowler and Fowler’s (1979) proposal that 11 areas of intimacy are active in a couple’s relationship. All of these arenas are not operative in non-couple dyadic relationships.

**Coping-reacting.** Areas of intimacy that relate to coping-reacting are social, recreational, economic, household, and physical health.

**Adapting-withdrawing.** Areas of intimacy that relate to adapting-withdrawing are parenting children, emotional, sexual, and intellectual.

**Growing-endlessly repeating.** Areas of intimacy that relate to growing-endlessly repeating are spiritual and the challenge and meaning of life work.

**Courage.** The key element to supporting courage in the caregiver-care partner relationship is finding ways that the couple or dyad can be mutually encouraging despite the effects of dementia on the behaviors of the care partner and the effects of the dementia journey on the behaviors of the caregiver. The key sign of discouragement in the relationship is withdrawal from one another. Engagement and repeated attempts, despite sometimes limited success, identify a courageous relationship. In a sense, joining the dyad and remaining joined are the acts of courage.

**Encouraging the relationship.** The key to encouraging the relationship is to create
evidence within the dyad’s interactions that things they do together make a difference to how each one views the dementia journey and to how each one can approach the dementia challenges with resilience. Teaching about encouragement is nowhere as effective as demonstrating, live, with each that the members of the dyad can make a difference for each other.

**Encouraging Resilience in the Family**

Thirty-two percent of family or other unpaid caregivers have been helping for at least 5 years; 39% for 1 to 4 years (AA, 2009). Some people live 20 or more years after the dementia diagnosis.

Given such a time commitment, it is not surprising that one of the primary sources of discouragement for family members is society’s essentialist notion of dementia as forever debilitating to those around the person with dementia. Absent a self-generated story about what is happening, people, especially gathered together as families, look for society’s dominant stories in their own experience in order to make meaning of that experience.

Joining the family is a matter of listening to members’ current constructions of their situations, demonstrating empathy, understanding their social and medical contexts, and assisting them to reconstruct, if necessary, the family’s construction of the meaning, in order to set goals for coping, adapting, and/or growing.

**Assessment.** The family engaged together in a dementia experience comes in many configurations. For a couple dyad, the children, spouses, and children of adult children are often included as well as parents or siblings of the couple. The parent-adult child dyad could expand to include the spouse of the person with dementia (who may or may not be the parent of the adult child caregiver), as well as siblings, spouses, and children of several generations. In other words, any construction of family could be walking with the person with dementia on his or her journey.
Assessment of family in encouraging dementia resilience focuses on interactions and engagement of family members with the person with dementia and the caregiver. Instead of understanding the family system in its whole, the effort is to tease out the impact of family on the resilience of the critical players on the dementia journey. Of course, the broad family system will impact the ability of family members to encourage the caregiver and the person with dementia.

**Stage of family development.** Many people with dementia are in their 70s or older. This can speak to the stage of their own family development. However, because the impact of dementia can affect many generations in a family, the family’s development is not apt to be describable as a singular stage. In addition, because dementia is not limited to the elderly, with young-onset Alzheimer’s disease and frontal-temporal dementia sometimes beginning in the early 40s, dementia families may have almost any stage of family development. For this reason, it is useful to understand the unique developmental characteristics of each dementia family.

**Phase of the journey.** Caron et al. (2000) stage the dementia journey as phases that take place between transitional milestones when family roles and decisions change, rather than typical staging around levels of disability of the person with dementia. The phases are prediagnosis, diagnosis, role change, chronic care, shared care, nursing home, and end of the journey.

Using the seven phases in the Caron model provides an anchor for the family that emphasizes their role, making it feasible to describe the journey as one that the family takes rather than one the person with dementia takes. Assessment includes the phase the family is currently in as well as family members’ understanding and acceptance of the anticipated progression of the process they experience. Assessment also identifies the decisions typical to the phase which the family may be unable to navigate.

**How the family works.** Drawn from Benbow, Marriott, Morley, and Walsh (1993),
assessment targets include (a) feelings within and across the family about the diagnosis and about the person with the diagnosis and (b) family coping patterns and pre-existing conflicts among family members. Benbow et al. also note how well the family is currently working: (a) conflicts between member needs and needs of person with dementia, (b) indicators of elder neglect, abuse, or exploitation, (c) current crises and decisions needed, and (d) whether or not the family system has been mobilized on behalf of person with dementia and the caregiver.

Family members may come to an impasse or high level of conflict around: (a) who decides, (b) who works to cope, (c) who supports whom, (d) whose ethics apply, (e) who is experiencing the greatest loss, and (f) unresolved relational issues.

*Adlerian assessment.* Sherman and Dinkmeyer (1987) describe an assessment as including the following:

1. individual members’ view of main challenge and what should happen; who seeks and who resists change.
2. family atmosphere, that is, autocratic, democratic, permissive, friendly, or hostile.
3. family constellation, including intergenerational birth order positions.
4. levels of cohesiveness, cooperation, satisfaction, and social interest.
5. roles relative to family tasks as well as restrictiveness of roles. Roles are “reciprocal characteristic patterns of social behavior that each member of the system expects of one another. . . [and include] “a sense of moral entitlement” (p. 31).
6. communication patterns, including “withholding information, giving partial information, overgeneralizing, giving incongruent information, forgetting, and lying” (p. 35).
7. boundaries, differentiation, and coalitions.
8. patterns of transactions.
9. goals, priorities, myths, and beliefs.
10. family assets and extrafamilial resources.

Further, Sherman and Dinkmeyer (1987) recommend assessment of family dynamics, which can include how the family negotiates or makes decisions and which approaches to controlling others are acceptable, such as assertiveness or aggression, influence, and manipulation. Dynamics also include family intimacy, that is, degrees of paying attention, engaging, trusting and entrusting, and sharing.

With complex family configurations that include many generations and people from different families of origin, assessing the constellation and atmosphere of all families of origin may help uncover the sources for mistaken beliefs that stand in the way of the family’s ability to help the person with dementia and the caregiver.

**Meaning.** Families hold many meanings around being a family. Different members hold different meanings. Key family stories are deconstructed, embroidered, and otherwise deepened and re-authored now that a difference in a family member makes old and perhaps assumed roles inadequate. Kitwood (1997) cites Gray-Davidson’s insight that “the presence of dementia. . .may provoke a psychospiritual crisis in family members: ‘If we do not deal with our own issues of love, and grief around the failures of love, we cannot live with Alzheimer’s disease’” (p. 81).

Early recollections and other projective devices are appropriate ways to celebrate family and to explore other meanings of family, especially stimulating humor and other forms of dissent to society’s dominant constructions of dementia. “Who is in and who is out?” is going on in people’s minds and hearts, especially about the person with dementia. Those boundary concerns need to be brought into the family circle—hopefully in the presence of the person with dementia.
Another useful approach is to work with the psychological family (Boss, 2006), that is, those who regularly engage with the person with dementia. This may include friends and sometimes paraprofessionals. A focus on the family of origin may well complicate the therapeutic discourse beyond what is necessary to meet the purpose of intervening.

**Movement.** An important consideration in working with dementia families is to be clear about the purpose or level of intervention. The effort is not necessarily (a) to pursue every useless behavior on the part of every family member, (b) to heal every family dysfunction and (c) to create a healthy family. The effort is to make enough change in behaviors of the family members and system that there is room for attention to the well-being of the person with dementia and for support to the primary caregiver.

Conflict may generate the need for facilitation or mediation. However, the effort needs always to maintain a focus on the dementia journey, and only on past slights or grievances as they are obstacles to supporting the person with dementia or the caregiver. This is not to say that familial conflicts are always irrelevant. Some will be critical to improving the family’s capacity to make a difference.

Sometimes roles need to change significantly. Sometimes past events and relationships result in family members safeguarding. They cannot free themselves to deal with the new challenge to the family. Sometimes the present consequences of the past result in aggressive behaviors born of discouragement. Sometimes families continue to use one member as the scapegoat for family defeats and anxieties. These are all times to engage in family therapy.

**Coping-reacting.** Dividing up the duties is an important part of family coping and often creates conflict. Psychoeducation will help family members understand what is happening to the person with dementia. Learning as a family unit is a powerful way to build cohesion. To learn
that it is possible to continue communicating and connecting emotionally can relieve many anxieties that show up as reactive behaviors. Conspicuously appointing the caregiver as the expert, teacher, and facilitator of communication can be an effective intervention when the least powerful member of the family is the designated caregiver.

Potential sources for communication difficulties in the person with dementia were described earlier. The list does not, of course, take into account communication deficits and habits of family members who do not experience dementia. Due to the uniqueness of each person with dementia, “live” coaching may be more effective than lists of how to talk, listen, and interpret.

Any communication difficulty may prompt agitation as the patient becomes bewildered or feels overwhelmed. An agitated patient can be impossible to communicate with unless the family member has a great deal of patience or imagination. Therefore, the goal is to keep the frustration level of the person with dementia low by helping him or her to express thoughts and feelings. He or she will evidence less frustration when family members attend to his or her human needs to belong, be safe, and matter.

**Adapting-withdrawing.** Above all, the family works hard to keep the person with dementia in the family, re-working old roles and developing new ones. Loss of the former roles held by the person with dementia may now require creating new leaders, new decision structures, or new ways to get things done. In a sense, it may be useful to accept the withdrawal from the psychological family of those who wish to do so in order to concentrate resources and energy on those who wish to cooperate.

Another aspect of role-shifting is in the relationship between the caregiver and other family members. Neufeld and Harrison (2003) found a negative impact on caregiver health
when women caregivers’ negative interactions (particularly with kin) included the belittling of the caregivers’ experience, conflict over the health status of the care recipient, criticisms of care decisions, and spillover of long-standing family issues. More broadly, the major difficulty found in the study was the caregiver’s unfulfilled expectations for assistance, social interaction, and competent, well-matched help. These arose sometimes from offers that never came and sometimes from offers that were made but not fulfilled.

**Growing-endlessly repeating.** Primary effort toward growing as a family takes place in order to aid the person with dementia and the caregiver, where endless repetition gets in the way of care or quality of life. While now is not necessarily the time to fix the family, a threat to the established order can be a powerful motivator to growth of the family members or changes to the existing family system. Particularly in the fourth phase, chronic care, there are a number of issues which may require family growth, as identified by Caron et al (2000). These include (a) maintaining family energy in the face of threats to established order, (b) taking care of the caregiving systems in the face of potential need for renewal and replenishment, and (c) preserving the unique, connected features of the family life in the face of challenges to emotional intimacy.

**Courage.** Family courage comes through family stories. Especially as they contradict dominant societal assumptions and constructions, this may be because such stories foster a pulling together as in “us versus them.” Family stories can help or hinder the dementia family’s ability to cope, adapt, and grow, so finding the stories about thriving supports family courage. Rigid roles, boundaries, rules, and beliefs can interfere with coping. Therefore, stories about past flexibility and creativity will be family strengths.

Adapting via a new family structure, the psychological family, can be supported by the
strength of a family’s stories of times the family added or left members behind. Growth can proceed from building new narratives or capitalizing on insightful and imaginative abilities to re-author old stories. Finally, but not least, courage also comes from stories of times the family encouraged its members. The family finds courage as resilient behaviors arise from their new constructions of the dementia and family experiences.

**Encouraging the family.** Genogram or other family mapping is introduced as a way to capture the relationships within the family as well as re-form the network of stories that tell the meaning of the specific family. Evidences of social interest through the generations are noticed and affirmed. The family participates in developing a map, in effect, of resilient behaviors.

**Collaborative learning.** Another strategy is to provide learning experiences in an environment where learning is a collaborative venture. Support and expertise come from professional helpers around unusual and critical dynamics, roles, rules, and relationships. The family shares support to others and gathers support. One such collaborative learning environment is that of the Wayne Caron Family Caregiving Center (University of Minnesota, 2009). Anecdotal evidence supports the effectiveness of this model.

**Community that encourages resilience.** Another approach would be to focus less on learning and more on courage. An encouraging community of people with dementia, their caregivers, and their family members can move beyond coping to adapting and providing support for growing. The community of families joins forces to foster mutual expression of social interest, provide good will toward all families on their dementia journeys, and offer the opportunity to join in a cooperative venture with other families to enhance everyone’s well-being. Within this community, a web of relationships is formed through common psychoeducation around elements of the dementia journey and through provision of group
therapy experiences that go beyond support group efforts that solely assist with the coping challenges. The concept of purposive behaviors helps everyone interpret what the person with dementia says and does and helps caregivers and family members change from their own reactive behaviors to encouraging responses that develop from understanding the needs of the person with dementia.

Facilitated family meetings support the resilience of the family upon entry to the community, at key decision points, and when conflict arises. Therapy for the person with dementia, the caregiver, and the caregiving dyad emphasizes the comprehensibility of the journey and the opportunity for change in the relationship or growth in the individuals. Being based on resilience rather than ambiguous loss or trait-based resilience models, the encouraging community accepts and understands the real-world complexity of the journey and helps its members meet the challenges of coping, adapting, and growing. The encouraging community is a cooperative venture in resilience.

**Summary of Encouraging Ways of Being**

The basis for encouraging dementia resilience is to exhibit behaviors that expose the cooperation skills and social interest of the professional helper and all the people on a dementia journey. Cooperation and social interest rise from convictions such as the following:

1. Each individual with dementia is a unique instance and in that individuality lies his or her continuing personhood.

2. To rest in the dementia experience on a feeling of superiority (caregiver or family member) or total inferiority (person with dementia) are both signs of refusal to grow.

3. Social interest is keeping self and the other on a horizontal plane when one has a cognitive deficit—fellow human of equal value to fellow human.
4. At its simplest, courage is the willingness to cooperate with others. At its simplest, encouragement of a person with dementia is being present for the interactions and intentions he or she offers.

5. Behaviors communicate purposes more strongly and more forthrightly than words. Words, in fact, are not necessary to communicate purpose, intentionality, creativity, or emotion. Behaviors will suffice.

6. Mistaken goals and behaviors are just that—mistakes along the way.

7. “To encourage is to promote and activate the community feeling, that is, the sense of belonging, value, worthwhileness, and welcome in the human community” (Griffith & Powers, 2007, p. 20).

8. Everyone involved can count on the fact that others want to connect, count, be capable, and have courage. Everyone can understand others’ striving for perfecting the self to the ideal because of their own struggle to rise through the same striving to overcome imperfection. Everyone can be as patient with others’ safeguarding, side-stepping, hesitating behaviors as they would expect patience. Everyone can recognize that others’ striving to be safe, to belong, and to matter or be significant is as motivating to them as is their own.

9. Courage grows through being willing to turn aspects of the psyche that seem to be individual and internal over to the interpersonal and relational.

10. The best strategy to gain courage is to encourage someone else. Everyone responds to encouragement. It is a powerful connector.

11. Resilience arises from the willingness to act directly, displaying the courage to be imperfect.
12. Post (2000) lays the matter before us all in chiding “rather than thinking of people with dementia as out of reach because of forgetfulness or as unworthy because of cognitive disability, the moral task it to bring them into discourse in creative ways. . . . One act of discourse is the extension of the hand, another is the tone of voice that reassures the person” (pp. 94-95).

Kitwood (1997, p. 69) sums up the best elements of the dementia journey. “Memory may have faded, but something of the past is known; identity remains intact, because others hold it in place; thought may have disappeared, but there are still interpersonal processes; feelings are expressed and meet a validation response; and if there is a spirituality, it will most likely be of the kind that Buber describes, where the divine is encountered in the depth of I-Thou relating.”
References


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2008


ENCOURAGING DEMENTIA RESILIENCE


Figures

Figure 1: Elements of Adlerian Lifestyle and Their Inter-Relationships

Figure 2: Two Sides of Courage/Discouragement Coin

Figure 3: Dance of Encouragement/Discouragement
Elements of Adlerian Lifestyle and Their Inter-Relationships

- Will to compensate or overcome
- Will to belong, be safe, and be significant
- Will to make sense of self, others, and the world

- Private logic
- Perception
- Event
- Life to age 4 or 5

- Biased apperceptions
- Feeling of inferiority

- Interpret/meaning
- Convictions and beliefs
- Pattern of striving to overcome

- Courage creates spirit to overcome
- Discouragement creates safeguarding

- Fictionate goal
- Behavior that fulfills purpose
- Lifestyle-generated purpose

- Social interest
- Self-sustaining loop
Two Sides of Courage-Discouragement Coin

coping
resilience
adapting

growing or transforming
discouragement
reacting
endlessly repeating same behavior
withdrawing
Dance of Encouragement-Discouragement

<table>
<thead>
<tr>
<th>Discouraged Person</th>
<th>Interacting Person</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MISTAKEN GOAL: ATTENTION</strong></td>
<td><strong>REACTION</strong></td>
</tr>
<tr>
<td>1. Feels insecure and alienated.</td>
<td>1. Feels irritated, annoyed.</td>
</tr>
<tr>
<td>2. Believes: <em>I belong only when I’m being noticed.</em></td>
<td>2. Thinks: <em>What, are you doing that again?</em></td>
</tr>
<tr>
<td>3. Behaviors: repeated questions, shadowing, ask for help but never accept answers, interrupt with words or sounds, ask question about care but never be part of decision-making, show suspicion, cry.</td>
<td>4. Impulsive behavior: remind, coax, lose patience, show irritation.</td>
</tr>
<tr>
<td>5. Response behavior: temporarily stops but later resumes same or another attention-seeking behavior.</td>
<td></td>
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</tbody>
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<table>
<thead>
<tr>
<th>UNDERLYING PURPOSE: CONNECT</th>
<th>ENCOURAGING BEHAVIOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feels secure.</td>
<td>1. Replace with positive attention.</td>
</tr>
<tr>
<td>2. Believes <em>I belong.</em></td>
<td>2. Do “together” activity or decision-making</td>
</tr>
<tr>
<td>3. Switches to positive goal: cooperation.</td>
<td>3. Ignore behavior, not person.</td>
</tr>
<tr>
<td>4. Find other connections which discouraged person can initiate.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>MISTAKEN GOAL: POWER</th>
<th>REACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feels inadequate, dependent, controlled by others.</td>
<td>1. Feels angry, challenged.</td>
</tr>
<tr>
<td>2. Believes <em>I’m nothing if I let you make me do this or let you stop me.</em></td>
<td>2. Thinks: <em>I insist you do it my way. Just do what I tell you to do.</em></td>
</tr>
<tr>
<td>3. Behaviors: criticize suggestions from family member, stubborn refusal to (for instance, get undressed for bath), argue, refuse to let other family members “win” in care decisions, complain about what don’t get to do, refuse to go somewhere, insist there’s one right way, cry, angry outburst, lie, argue.</td>
<td>4. Impulsive behavior: fight for power, never let issue be closed, try new ways to get or maintain control.</td>
</tr>
<tr>
<td>5. Response behavior: escalation or intensification of behavior.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>UNDERLYING PURPOSE: CAPABLE</th>
<th>ENCOURAGING BEHAVIOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Feels competent and in control of self.</td>
<td>1. Resist trying to win.</td>
</tr>
<tr>
<td>2. Believes <em>I can do it. I am worthwhile.</em></td>
<td>2. Give opportunity and choices to show power and control constructively.</td>
</tr>
<tr>
<td>3. Switches to positive goal: self-reliance.</td>
<td>3. Divert attention.</td>
</tr>
</tbody>
</table>

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*Connect, capable, count, courage are the Crucial C’s (Bettner & Lew, 1989). Dance of Discouragement/Encouragement is based on the Crucial C’s tool for working with children’s mistaken behaviors (Bettner, 1996). Mistaken goals of behavior (Dreikeurs & Soltz, 1964).*
**Discouraged Person**

- **MISTAKEN GOAL: REVENGE**
  - Feels insignificant.
  - Believes *I knew you were against me. No one likes me. I must show you how it feels.*
  - Behaviors: take away things or choices; destroy, steal, or hide things; attack other’s weaknesses; suspicions that focus on other’s character, risky actions, threats of separation or suicide, lie.
  - Response behavior: acts to provoke being disliked or to get back or get even.

- **UNDERLYING PURPOSE: COUNT**
  - Feels significant, valuable.
  - Believes *I matter. I am worthwhile. I can make a positive difference.*
  - Switches to positive goal: contribution.

- **MISTAKEN GOAL: AVOIDANCE**
  - Feels inferior, useless, hopeless.
  - Believes *I can’t do anything right so I won’t try. If I don’t try, my mistakes won’t be so obvious.*
  - Behaviors: withdraw from contact with other or family member; unwilling to participate in activities or rituals; withdraw from support systems; resist new situations or ones that have become uncertain; refuse to try to do things; stop trying old solutions after one failure.
  - Response behavior: passive, no changes, more hopeless, displays of inadequacy.

- **UNDERLYING PURPOSE: COURAGE**
  - Feels hopeful, willing to try.
  - Believes *I can do it. I am safe trying.*
  - Switches to positive goal: determination to try.

**Interacting Person**

- **REACTION**
  - Feels hurt.
  - Thinks: *How could you do this to me? I’ll teach you a lesson.*
  - Impulsive behaviors: punish, get even.

- **ENCOURAGING BEHAVIOR**
  - Avoid hurt feelings.
  - Maintain appreciation.
  - Provide opportunities to help.
  - Seek support and help in identifying positives.

- **REACTION**
  - Feels despair, hopelessness.
  - Thinks: *It’s no use. I quit. I can’t wait to quit.*
  - Impulsive behaviors: give up, back away, keep same roles as always, not call on family member to step up to challenges.

- **ENCOURAGING BEHAVIOR**
  - Notice only strengths and ignore the negative.
  - Find and share the humor.
  - Set up steady exposure to manageable tasks that guarantee success.
  - No criticism.
  - Try out incremental role changes while maintaining task for discouraged person.
  - Don’t give up.
  - Find even a small way to cope, adapt, or transform.