

The Caregiving Principle™: For A Less Stressful, More Rewarding Journey

Carol B Amos*

CARES Dementia Specialist, Hockessin, De United States

*Corresponding author: Carol B Amos, CARES Dementia Specialist, Hockessin, De United States, E-mail: carol1de@aol.com

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Abstract

Caring for persons living with Alzheimer's disease is difficult because of the impact of the disease on their cognitive functions. Ms. Carol Amos, the family caregiver, realized that her success as her mother's caregiver was based on her relationship with her mother, Ms. Elizabeth Boyd. During the early phases of the disease, some difficult interactions arose and Ms. Amos wanted to prevent these from recurring. Carol reflected on her mother's condition, analyzed these tenuous situations, evaluated her caregiving, and developed The Caregiving Principle™. The fundamentals of The Caregiving Principle™ provided additional insight into her mother's thinking and helped to improve their interactions. The Caregiving Principle™ is a novel approach to Alzheimer's caregiving to make the journey less stressful and more rewarding. The Caregiving Principle™ is introduced in the book H.O.P.E. for the Alzheimer's Journey: Help, Organization, Preparation, and Education for the Road Ahead.

The Caregiving Principle™

Ms. Boyd became a widow in 1987 and adjusted to living alone. Ms. Amos and her brothers, living in other cities, visited most holidays. They provided some level of caregiving to their mother for the last fourteen years of her life. Initially, this assistance might be advice on minor household issues. As their mother's Alzheimer's disease progressed, she required more help from family and then from professional caregivers. Ms. Amos soon found that the degree of caregiving required was related to the needs of the person and his or her capability. This fundamental concept is called The Caregiving Principle™.

Needs of the Person – Needs To be Filled by the Person=Needs to Be Filled by the Caregiver(s)

To put it simply, if a person cannot provide for all of his or her own needs, then someone else (caregiver) must provide them. For example, apply the principle to a baby and think about how the parent's responsibilities change as the baby becomes a toddler, a teenager, and then a young adult. The Caregiving Principle™ was developed with a person with Alzheimer's in mind but it can be applied to any person.

Needs of the Person

The Caregiving Principle™ broadly defines the needs of a person, which consists of much more than ensuring that activities of daily living (ADLs), such as bathing, dressing, and eating, are met [1]. American psychologist Abraham Maslow defined needs in a way that encompassed the total being. He believed everyone has five levels of needs (Figure 1). A person does not have a desire for a need on the upper part of the pyramid until the needs on the lower part, are mostly met. The size of the pyramid section shows the magnitude of the need. For example, a person has a need for food (physiological) every day but may only have a need for self-actualization once per month, or possibly never.

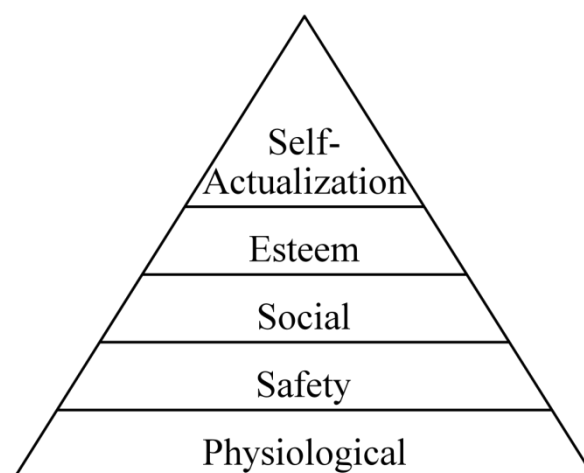


Figure 1: Maslow's Hierarchy of needs [2].

Based on this concept, the needs of a person are:

- Physiological-air, food, water, and sleep
- Safety-personal security, financial security, health, and well-being
- Social-friendship, intimacy, and family
- Esteem-respect, self-esteem, and the need to be accepted and valued by others
- Self-actualization-the need to realize one's maximum potential

Maslow states that if the physiological need (air, food, water, and sleep) of a person is not met, then this deficiency will have a physical impact on the body (for example, dehydration, constipation). When the safety, social, and esteem needs are not met, the deficiency may affect the mind and behavior: "The body gives no physical indication, but the individual feels anxious and tense [3]."

Anxiety is one of the behaviors exhibited by persons with Alzheimer's [4]. When Ms. Amos reviewed some of the conflicts with her mother, the root cause was Mrs. Boyd's instinct to meet one of these five needs. Ms. Amos believes that many Alzheimer's behaviors, such as anxiety, aggression, suspicion, and hallucinations, can be a result of an unfulfilled physiological, safety, social, or esteem need. To help manage behaviors, the Alzheimer's Association brochure on behaviors advises caregivers to determine whether the person's needs are being met [3]. Ms. Amos finds that both understanding and meeting the physiological, safety, social, or esteem needs of a person can reduce his or her anxiety and alleviate some of the behaviors.

Before an Alzheimer's diagnosis was made, the individual met most if not all of his or her needs independently. Meeting all of the needs of a person living with Alzheimer's provides a good quality of life. However, applying Maslow's Hierarchy of Needs to a person with Alzheimer's may appear to be a daunting task for a family caregiver. In many cases, supplying the first two needs (physiological and safety) requires much more than many caregivers can physically and mentally handle. The primary caregiving focus should be to provide the lower needs of the pyramid such as eating, bathing, sleeping, health, and safety in a way that maintains the person's esteem. Family members or friends not directly involved with providing care can help meet his or her social or self-actualization need. As the illness progresses, the first two needs (physiological and safety) will require more of the caregiver's time, and the person may show less need or appreciation for the needs on the upper portion of the pyramid.

Physiological need

The physiological need is the most important one in the pyramid. Maslow defines the physiological need as the basic needs of the body to survive, such as food, water, sleep, air, and excretion [5]. These basic needs are similar to activities of daily living (ADLs) a set of common, daily tasks needed for personal care and independent living that include transferring, toileting, bathing, dressing, eating, and sleeping.

Instrumental activities of daily living (IADLs) are tasks that support the ADLs, such as cooking, cleaning, and managing finances [6]. The failure, inability, or poor quality in which a person carries out his or her IADLs is usually an indicator that the loved one is having difficulty with memory. IADLs require memory, reasoning, and judgment skills that are declining in a person in the early stages of Alzheimer's disease. The physiological need, as defined in the Caregiving Principle™, encompasses ADLs and IADLs as well as providing shelter.

Safety need

Maslow's definition of safety encompasses "freedom from fear, from anxiety and chaos." He suggests that children will not feel safe if confronted with some new, unfamiliar, or strange situations [7]. These same situations can make a person with Alzheimer's feel less secure. Routines and familiar people and surroundings provide a sense of security required by a person with Alzheimer's. In fact, the need for this security is crucial.

The safety need also includes physical safety at home and away, financial security, and good health [2]. An elderly person may feel safe and secure at home but still has unsafe routines and lives in an unsafe environment. Safety should be the first concern addressed by family members of the elderly. A person with Alzheimer's is at increased risk for injury because of lack of judgment, and this risk increases as the disease progresses.

The elderly have a great need for financial security. They never want to be "a burden on anyone." Some residents of memory care facilities might even believe that they are employees and this eases their financial concerns.

Social need

The social need is the need for belonging, love, and affection. If this need is not met, the person will experience feelings of alienation, strangeness, and loneliness. Periodically scheduling a social outing, even with another family member or friend, helps to fill the social need and improves the quality of life for a person with Alzheimer's. The caregiver should take advantage of periods when not many issues are pressing. Social opportunities often create a time when the loved one remembers engaging in similar activities earlier in his or her life. Family and friends can call, visit, take the person for a ride, or have the person help with a project (plant flowers, fix a faucet, etc.).

Esteem need

The esteem need is defined as a "desire for a high evaluation of themselves for self-respect or self-esteem, and for the esteem of others." It includes a desire for achievement, independence, status, dignity, or appreciation. Satisfaction of this need leads to feelings of self-confidence and worth. If the esteem need is not met, the person will have feelings of inferiority and helplessness [3].

Self-actualization need

The highest need in the pyramid is self-actualization, defined as man's desire for self-fulfillment or accomplishing what a person is capable of becoming. A person only has a need for self-actualization when the other needs are met [3]. A person with or without Alzheimer's may not have a need for self-actualization even if all of his or her other needs are met.

Ms. Amos evaluated her mother's needs using Maslow's theory and it helped her understand Mrs. Boyd much better. For example, to meet a physiological need, Mrs. Boyd kept a glass of water in her room. Mrs. Boyd was uncomfortable leaving her facility because the memory care area had become a safe and familiar environment and met her need for safety. She

frequently asked how the family was doing so she satisfied her social need by hearing family news. At times, Mrs. Boyd tried to mask her Alzheimer's. Often, in the doctor's waiting room, she would whisper to her daughter, "What doctor am I here to see, and what am I here for?" She was trying to maintain her esteem. Moreover, she cared about what others thought about her. Ms. Amos once made a comment about the caregivers helping her mother take a shower, and Mrs. Boyd replied, "I'm not helpless. I don't need help getting a shower." Mrs. Boyd wanted to operate at her maximum potential (self-actualization) even when her cognitive and physical states were declining.

It was truly eye-opening when Ms. Amos applied Maslow's Hierarchy of Needs to a situation with her mother. Ms. Amos' husband Alvin brought Mrs. Boyd to their house on Thanksgiving Day, 2009. She enjoyed the fellowship but started to ask some variation of the same question. "How did I get here?" "Is my car parked out front?" The Thanksgiving meal met her mother's physiological need. The visit and the interaction with Mr. and Ms. Amos met her social need. After dinner, Ms. Amos had planned to play Wheel of Fortune because Mrs. Boyd enjoyed watching the show on television. Ms. Amos wanted to test whether the game would be stimulating or frustrating for her. But Mrs. Boyd did not want to play. She wanted to return home (the memory care facility) because home provided her with the safety she needed. Until her need for safety was fulfilled, she had no desire for additional social activities. Understanding Mrs. Boyd's need for safety prevented Ms. Amos from being upset. Ms. Amos knew why she wanted to go home, so her daughter returned her to memory care and went Christmas shopping afterward. Mrs. Boyd was content, and so was Ms. Amos. Throughout the years, Ms. Amos and her brothers had many conflicts with their mother. Using The Caregiving Principle™ to understand Mrs. Boyd's needs could have helped in many of those early situations.

Needs Filled by the Person

The second component of The Caregiving Principle™ is "Needs To Be Filled by the Person." These needs are filled based on the cognitive capability (which declines as the disease progresses) and the physical ability (which declines with age and as the disease progresses) of the person. Caregivers should proactively try to slow the decline of the individual's cognitive capability and physical ability so that the person can continue to care for him or herself. The ability to care for his or herself increases self-esteem and also reduces the financial expense and the toll that caregiving takes on family and friends.

Cognitive capability

Caregivers should consult with a dementia specialist for a diagnosis and the start of treatment. They should focus on three areas to help maximize the capability of a person living with Alzheimer's. They are:

- Maintain routine. Routine provides a sense of comfort and familiarity and helps to meet a person's need for a sense of security

- Minimize anxiety. Minimizing anxiety helps the person's need for a sense of security and allows him or her to focus on the task at hand. Techniques such as redirection and "live in the patient's world" [6] can help defuse anxiety in persons living with Alzheimer's
- Engage in stimulating activity. Stimulating activity may slow the mental decline and help a person reach his or her full potential (self-actualization)

Physical ability

Normal physical changes in an aging body include slower reflexes, arthritic joints, loss of peripheral vision, and decreased mobility. Providing medical care can help loved ones continue to look out for themselves. Consult with a doctor to determine what screenings are appropriate based on age and family history. Caregivers must evaluate the benefits and risks of medical procedures. Regular medical visits can improve the quality of life of a loved one.

Needs to be Filled by the Caregiver(s)

The last component of The Caregiving Principle™ is "Needs to Be Filled by the Caregiver(s)." It defines the role of the family caregiver. Caregiving can involve one or multiple families, friend, or professional caregivers. For instance, one caregiver may focus on the person, such as feeding or bathing, and another may focus on household support, such as cooking or laundry. If the loved one resides in a facility, the facility will meet the basic needs, and family members can supplement this care to provide a good quality of life. Family caregivers often have at least four responsibilities vying for their time. They are:

- Take care of yourself
- Ensure that the needs of your loved one are met
- Manage indirect caregiving details (medical, financial, legal, insurance, etc.)
- Meet other responsibilities (family, work, community, etc.)

Because a person can live ten or more years with the disease, family caregivers must reach out to other family members and professionals to keep from being overwhelmed with caregiving responsibilities.

Conclusion

The Caregiving Principle™ is a simple and effective approach to Alzheimer's care for the family or professional caregiver. The benefits of the principle are:

- It utilizes Maslow's Hierarchy of Needs to provide caregivers with a deeper understanding of the person living with Alzheimer's
- It highlights the importance of minimizing the physical and cognitive decline of the loved one so that the person can meet more of his or her needs
- It emphasizes that the caregiver needs to proactively prepare for increased caregiving demands as the loved one declines
- It helps identify the role of the family caregiver

Caregivers can be easily taught The Caregiving Principle™ so they can apply the concepts to their own situation and have a less stressful and more rewarding caregiving experience.

Acknowledgment

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