



Caring for the Individual with Dementia Kelly O'Shea Carney, PhD, CMC

Caring for someone with Alzheimer's disease can feel like trying to hit several moving targets all at one time -- and with one arrow. As the disease progresses, the nature and substance of the individual's needs change and grow increasingly complex. Often, just as a caregiver begins to feel as if they have figured out what works best for their loved one, the strategies and approaches learned may no longer be effective. As the needs change, the perspective and approach of the caregiver must also change and the effort to keep up with the "moving target" can be frustrating and exhausting.

In order to effectively target caregiving approaches to the evolving needs of the individual, the caregiver must engage in an ongoing process of education, self-assessment and creative problem solving. This process of altering caregiving in response to the changes in the individual can be daunting and is often most effective when the caregiver utilizes available resources to guide their efforts. Caregiver education and support, as well as the guidance of professionals skilled in dementia care, can be critical to ensuring that the caregiver is successful in understanding and addressing the changing needs of the individual with advancing dementia.

In an effort to understand the "moving target" presented by Alzheimer's disease, it may be helpful to consider the key caregiving tasks and challenges in the early, middle and late stages of the disease. While a three stage model represents only a simplistic breakdown of disease progression, these broad categories can be helpful in describing the primary shifts in caregiver responsibilities that occur over the course of the disease. It is also important to note that within each stage there are a variety of needs to be met, including biological/medical, psychological and social. These intersecting "biopsychosocial" needs, which evolve from one stage of the disease progression to the next, form the framework for effective care planning, whether the individual resides at home or in a care facility.

In the earliest stages of Alzheimer's disease, the individual affected by the disease is likely to have some understanding and awareness of the changes that are occurring in their thinking and behavior. This awareness can result in a great deal of anxiety, sadness and distress for both the individual and the family

caregivers. Providing emotional support at this time of great stress becomes one of the main tasks of the caregiver, and at the same time, the caregiver must find ways to manage their own distress over the diagnosis. In addition, the individual with Alzheimer's disease may lack insight into their emerging functional limitations, and as a result, may have difficulty appreciating what they can and cannot safely do. For example, the individual may feel that they can still safely drive a car, in spite of multiple accidents or the advice of a physician to the contrary. In these situations, the caregiver is faced with the task of actively determining when and how and how much of life's daily activities the individual can still do independently, while sensitively assuring that assistance is provided. Finally, as the individual's cognitive skills decline, participating in large group events or even small social events may become more difficult. The person may feel disoriented by the activity and complexity of social interactions in groups or may be fearful that their cognitive deficits will become obvious to others. Helping the individual with dementia to find the right balance of social activity within settings and groups that are comfortable is another task the caregiver will face.

In the middle stages of disease progression, the individual with Alzheimer's disease is likely to demonstrate clear cognitive deficits that interfere with independent activity and function. The individual is likely to need assistance with their basic self-care and personal affairs, including medication management, hygiene and more complex tasks, such as paying bills or managing a schedule. In addition, diminished insight, safety awareness and judgment are also common in this stage. As a result, the caregiver often must provide increasing levels of supervision to ensure that their loved one is safe, while also somehow managing all the day to day tasks of the home, finances and self-care. In the middle stage of progression, challenging behavioral expressions may also occur, such as angry outbursts, refusal of assistance and or engaging in dangerous behavior like wandering or attempting to use the stove unsupervised. It is at this stage that the caregiver may feel that they need eyes in the back of their head and additional hands just to keep up with the basic needs for safety and health. Meanwhile, it is also important at this stage for the individual to engage in meaningful activity each day and to have interactions with others that meet their emotional needs. Providing opportunities for safe and meaningful engagement in activity and socialization each day can require a great deal of creativity and initiative by the caregiver. Given the breadth and complexity of caregiver activities at this stage, it is important that the caregiver seek support and resources needed to assist in the task. The job of meeting all the medical, safety, emotional and social needs of the individual is simply too overwhelming for one person to manage alone.

In the late stages of Alzheimer's disease, the cognitive and functional losses are profound, rendering the individual completely dependent upon others for care. In

this stage, the ability to communicate is generally quite impaired, making it difficult to engage in verbal communication. As a result, meeting the psychosocial needs of the individual requires greater use of touch, sensory experiences and non-verbal communication. Hugs, smiles and backrubs become primary methods of communicating that the individual is loved and cared for. Opportunities to enjoy music, pets, touch, favorite foods or scents may become primary sources of connecting the individual to the world around them and engaging them in a meaningful way. In addition, physical and medical needs are likely to take precedence in this final stage of the disease. Substantial hands-on care is likely to be necessary to ensure the individual's well-being, including feeding, toileting and bathing. This stage can be the most exhausting because of the physical demands of caring for a dependent person. In addition, the caregiver is likely to need a great deal of emotional support during this last stage, as it marks the end of the "very long goodbye" with the individual with Alzheimer's disease. Many caregivers find that they experience a kind of anticipatory grief as they provide care through this final period.

In sum, the task of caring for an individual with Alzheimer's disease over the course of the disease progression is complex and demanding. Not only does the job require a high level of physical stamina, but it also requires the caregiver to be intellectually engaged in a process of assessment, review and revision as they adjust their perspective and focus on the emerging biopsychosocial needs of the affected individual. The complexity of the task demands the addition of resources to augment the role of the caregiver. In a care facility, an entire team of people would be engaged in the work of assessing and addressing the emerging needs of the individual. Therefore, it is unrealistic to believe that any individual caregiver can manage the task alone. As the target moves and the needs evolve, it is imperative that the caregiver take stock of what is needed and reach out for help in the areas that they cannot effectively manage alone.

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