

Dementia capable care insights

Five reasons to identify the disease stage of individuals with dementia

*Editor's note: "Dementia capable care insights" is a new, semi-regular column written by **Kim Warchol, OTR/L, DCCT**, president and founder of Dementia Care Specialists, a specialized offering of CPI, a Milwaukee-based training and consulting firm. It will explore the latest research, best practices, and regulations to help long-term care providers navigate the evolving dementia care landscape. To submit a dementia care question or topic for discussion, email Associate Editor Delaney Rebernik at drebernik@hcpro.com.*

A person diagnosed with Alzheimer's disease or a related dementia will often go through rather predictable stages of the disease. For example, a person is often first diagnosed in the early stages of dementia and will gradually decline over many years, eventually progressing through middle, late, and end-stage dementia. Each stage is typically characterized by a progressive loss of ability to complete activities of daily living (ADL) and instrumental activities of daily living (IADL). Specific declines associated with each stage are outlined below:

- **In the early stage**, the person will experience cognitive changes such as difficulty solving problems, poor judgment, and trouble learning something new. These changes interfere with the independent and safe performance of IADLs, such as the ability to handle finances, drive, cook, and manage medications. Later in this stage, a person may begin to experience changes in ADL functioning, with noticeable alterations in the quality of activity performance. For example, the person may change clothes less often, make inappropriate clothing selections for an event or weather condition, and may not bathe as often as usual.
- **In the middle stage**, ADL functioning is very noticeably impaired because the person can no longer sequence him- or herself through each step of an activity. This individual will require one-on-one support to participate in ADLs such as getting dressed or eating a meal.

- **By the late stage**, most ADLs are completed by care partners because abilities have been severely compromised. The person may not be able to use objects or tools he or she once could or have very poor attention span and communication abilities. The exception, however, is self-feeding. Individuals at this stage maintain their ability to hold a cup or finger food and feed themselves at least part of a meal.
- **By the end stage**, the individual requires total assistance for all aspects of daily living but can still feel and express love and other emotions.

Identifying the stage of dementia in which the person with Alzheimer's/dementia is currently functioning is an essential assessment step. The stage of dementia is extraordinarily informative; it's like having a care road map. If we understand the characteristics of the stage one of our residents is in, as well as the deficits and remaining abilities associated with it, we can then understand how to enable this individual to successfully coexist with his or her disease throughout the care journey.

I often say the value of understanding a dementia stage is comparable to that of understanding the developmental age of a child. The age informs us how we must adapt for the child to be safe and successful. It helps us to set our expectations and predict functional independence, ability, and behavior responses. A dementia stage, when used appropriately, can have similar value.

There are many ways in which a dementia stage can inform and guide our care, including influencing daily clinical approaches, inspiring the design of the care environment, and informing the quantity of staff necessary in the nursing home. I will highlight five of the many important ways identifying a dementia stage can help guide care for affected individuals:

1. **By revealing functional performance potential and setting our expectations.** Cognitive capacity is the primary predictor of functional capability. Cognition underlies and drives functional

performance. We can correlate stages of dementia to functional ability level as detailed in the sidebar to this article.

2. By helping us understand how we can adapt to facilitate resident success. At each dementia stage, a resident retains certain abilities. We must capitalize on these abilities and compensate for the cognitive functions lost. Parents adapt the world for children of all ages to ensure they feel and become successful. Those providing care for individuals with dementia must take the same approach. Once we understand the characteristics of a stage and its functional performance expectations, we can adapt activities to provide just enough of a challenge to help residents exercise their abilities.

3. By helping us recognize patterns to manage challenging behavior. At each stage of dementia, there are some typical mood and behavior changes. If we are aware of these common shifts, we can become more prepared to care for residents effectively, in part by facilitating more positive feelings and responses. For example, a person in the early stages may believe one of his or her personal items (e.g., a purse or bag) is being stolen when he or she might have simply misplaced the item—a common symptom of early-stage dementia. Armed with this information, we can help a person to feel less suspicious and more in control by, for example, having multiple quantities of the item in question so that if it is misplaced, we can come to the rescue with another.

4. By allowing us to establish a proactive plan to minimize the chances of risks becoming realities. There are common health and safety risks at every stage of dementia. For example, medical problems arising from falls, infections, or over-/undermedicating are often seen in the early stages. People in these stages may still be trying to manage their everyday activities alone but prove unable to do so without some assistance. If we provide the correct amount of oversight and support for IADLs (e.g., taking medications) during early stages, these individuals will be at less risk to over- or undermedicate. In addition, if we check in on these residents every day, we can better observe hazards or behaviors that are putting them at risk for falls. We can then attempt to eliminate these hazards to keep these individuals safer.

5. By helping care partners maintain more control. The unknown is a scary prospect for many. Because the stages of dementia are rather predictable, they can bring comfort to a resident’s loved ones and other care partners by empowering them with the knowledge of what to expect in the moments, days, and years ahead. 

Source:

This column is a product of “The Warchol Report,” published by CPI.

Stages of dementia/functional ability levels	
Dementia stage	Highest level of independence possible
High early stage	<ul style="list-style-type: none"> - May need some minimal assist with IADLs (may not be able to drive) - Is independent with simple, familiar ADLs
Low early stage	<ul style="list-style-type: none"> - Needs one-on-one assist with IADLs (no longer capable of driving safely) - Begins to need some minimal assist for ADLs (e.g., reminders to change clothes)
Middle stage	<ul style="list-style-type: none"> - Needs extensive assist with IADLs (i.e., activities need to be almost exclusively done for the person) - Needs one-on-one assist for all ADLs, but can participate in aspects of ADLs with the appropriate adaptations and approach
Late stage	<ul style="list-style-type: none"> - Requires total assist for IADLs - Requires almost total assist for ADLs; however, can still participate in self-feeding with appropriate adaptations and approach
End stage	<ul style="list-style-type: none"> - Requires total assist in both IADLs and ADLs