Dementia Abilities Continuum

The Dementia Abilities Continuum can help families assess where their loved one might be with their dementia and what symptoms to expect. This continuum has three stages, which are meant as a general guide and not as absolutes. At different points in your loved one's illness, he may vacillate between one stage and another.

Mostly-Abled

In this first stage, your loved one most likely will have difficulty with short-term memory. It is common for her to be aware of these memory challenges and try to cover them up. It is not unusual for a person to become less aware of her cognitive and physical decline. This in turn can make it more difficult for her to accept help or to consider moving into a facility. You might notice the following symptoms:

- More forgetfulness than usual. She might misplace items more frequently, repeatedly ask the same question and not remember what has been said to her.
- More confusion.
- More difficulty with focusing.
- Struggling with tasks she was always able to accomplish, such as failing to keep up with bank accounts, bills or taxes.
- Struggling with finding the correct word.
- Experiencing feelings of embarrassment or shame from not remembering a familiar person's name.
- Beginning to withdraw from social functions, especially those in which she used to participate.
- Compensating for memory problems by trying to change the topic or by answering a question in a more generalized way.

For example, if asked how long she has lived in her home, instead of saying "30 years," she might say, "for a long time."

- Experiencing some paranoia, for example, accusing you or others of taking her money or jewelry.

Less-Abled

During this second stage, your loved one's long-term memory will become more impaired and her cognitive skills become more compromised. She may also begin to have some physical issues with balance, walking, and perception. She may have bladder incontinence. She may experience more confusion with performing her "activities of daily living" or ADL's, such as bathing, dressing, grooming, and food preparation. Her personal hygiene may suffer, along with her ability to stay properly nourished and maintain a clean and safe home environment. Some examples include:

- Being increasingly forgetful and unaware that she is not remembering, or asking the same questions over and over.
- Becoming more easily and more frequently confused. She may forget how to use the remote control or even get lost while driving to familiar places.
- Needing reminders to take a shower or change stained or dirty clothes.
- Having more difficulty with her attention span and following directions.
- Substituting the wrong word and jumbling her words in sentences.
- Beginning to lose some of her long-term skills and functioning. For example, she may not be able to remember easy tasks, such as how to follow a recipe or how to fix things in the house.
- Forgetting family members' names or details about her past.

- Having more difficulty with sitting still.
- Needing more supervision around safety. For example, your loved one might leave the stove on or have spoiled food in the refrigerator. She might make impulsive decisions due to an inability to think through the consequences, such as letting a stranger in the house.

Un-abled

At this third stage, your loved one's symptoms of dementia are quite severe. She now requires complete help with her ADLs and cannot function without continual supervision. The following typically characterize this stage:

- Mainly communicates through body language.
- Not aware of time, place or person.
- Being incontinent of bladder and bowel.
- Having more difficulty with eating and swallowing.
- Having more health problems, such as frequent infections. Urinary Tract Infections (UTIs) are particularly common due to incontinence.
- Not being able to walk, either needing to be in a wheel chair or recliner.
- Becoming bed-ridden.

In Summary

Understanding your loved one's abilities and strengths can help you identify more meaningful ways to be together. Assessing which stage your loved one is in can help you know what to expect, as well as help you engage most appropriately. The next chapter will offer tips and ideas about how to spend the best possible time with one another, regardless of the stage of dementia.

Learning to Observe

It is essential for care partners to learn to be good observers and pay attention to their loved ones' physical, cognitive, and social well-being. The questions below can help you determine their abilities.

As you work through these questions, I suggest that you write down your answers. This will help you consider ways to tailor your visit and interactions. Be mindful that over time, your loved one's abilities and capabilities will change and so will your answers.

Physical Questions

What physical challenges does your loved one have that can impact her ability to participate in activities and engagement?

- Does she have trouble hearing? Hearing abilities can certainly influence how well she will understand the information shared.
- Is her eyesight impaired? If she has trouble seeing, she can become more easily frightened or fearful, especially by sudden movements.
- Does she have special dietary requirements, such as a soft diet? This might mean planning ahead for outings that include meals.
- Is she prone to wandering or pacing? If so she can be at risk for getting lost or hurt.
- Does she have balance issues? Lack of balance can increase her risk for falling.
- Is she incontinent of bowel or bladder? This can restrict where you are able to take her.

Cognitive Questions

There are many cognitive symptoms of dementia that can impact engagement.

- Does he have short-term memory issues such as forgetting appointments, forgetting what you just talked about, or asking the same questions over and over?
- Can he follow conversations or understand verbal information? Is he able to process the information?
- Does he exhibit long-term memory issues, such as not remembering his family members, being unable to share where he grew up, or forgetting what career he had?
- Does he remember to take his medications as prescribed? Is he able to manage having medicines refilled in a timely manner?
- How long is his attention span? Can he remember what he has just read? Can he watch a movie or program through its entirety? Does he become easily distracted?
- Does he exhibit confusion and disorientation such as not knowing where he is, thinking he is still working, or thinking it is nighttime when it is daytime?
- Does he have difficulty with verbal expression? Does he mix up words in sentences, call objects by the wrong names, or struggle with expressing himself?
- Does he have some challenges with what are labeled as executive functions? For example, does he have difficulty with judgement and reasoning? Does he make impulsive decisions? Is he able to assess his safety?
- Does he have trouble performing familiar or routine tasks, such as keeping track of finances, paying bills, working the stove or microwave, or using the TV remote?

Social Questions

Researchers have demonstrated the importance of social interaction and engagement. Finding ways to keep your loved one engaged and involved in activities can have numerous positive effects. Here are some questions for your consideration about your loved one's social interactions.

- Is she still socially appropriate or has she lost her social filters? Social filters keep people from touching people or objects without permission, saying inappropriate things, cursing or swearing, or taking off their clothes in public.
- Is she able to initiate social activity? Often as someone loses more cognitive capacity, it becomes more difficult to initiate social activity.
- Is she able to function well in group activities? Does being in small or large groups cause your loved one to become more anxious or agitated?
- Does taking her out of her residential community or home cause anxiety or agitation? For example, does she get anxious in the days and hours leading up to a trip or outing? Is she uncomfortable and restless in a new environment?

As you keep these answers in mind, the "Dementia Abilities Continuum" is a tool that I created to help families understand common patterns of dementia and the disease progression.