



Changing Our Perceptions

of People Living With Dementia

CPI EXCLUSIVE DOWNLOAD

> **No matter what stage, a person living with dementia has abilities—things they can still do with assistance.**



About DCS and CPI

Dementia Care Specialists (DCS) provides state-of-the-art dementia care training, resources, and consulting services that help transform staff capabilities and quality of care. As a result, people living with dementia experience a higher quality of life, caregivers find more satisfaction, and providers improve their caregiving and business results. We believe that every person living with dementia has many remaining abilities that, when recognized and nurtured, can lead to a life of quality at each stage of the disease.

CPI is the standard in behavior intervention training that equips employees to have an immediate, tangible, and lasting positive impact on the people and organizations they serve.

Part of a series, this guide describes how family members, friends, or volunteers can use DCS principles and strategies to support those living with dementia.

You will learn:

- Working definitions for dementia, as well as Alzheimer's disease and related dementias (ADRD).
- How to focus on and maximize the remaining abilities of a person with dementia.
- How to identify characteristics of a person who is progressing through the stages of dementia.
- How to identify examples of developmental abilities and cognitive function for each stage.

Self-Assessment

The following questions are intended to help assess your current perspectives and understandings about people living with dementia. Think about someone you know living with dementia and answer the questions to the best of your ability.

1. In your own words, define dementia.

2. What are the words, phrases, or descriptors that come to mind when you think of someone living with dementia? Examples: “Angry and easily frustrated” or “Can no longer care for themselves.”

3. **True or False** Alzheimer’s is the most common type of dementia.

4. **True or False** No matter what stage, a person living with dementia has abilities — things they can still do with assistance.

5. On a scale of 1–5, how effective would you say you are at interacting with a person living with dementia? (1 = Not very effective; 3 = OK; 5 = Very effective)

1 2 3 4 5

Self-Assessment Answers

1. Answers will vary and may speak to a group of symptoms, a progression of stages, or when cognitive function interferes with daily living.
2. Restate answers so that they reflect the person's remaining abilities. Choose language like "can express their feelings clearly" versus "is easily angered and frustrated." Choose "is able to dress themselves with verbal prompting and assistance," versus "is no longer able to care for themselves."
3. **True** Alzheimer's is the most common type of dementia.
4. **True** No matter what stage, a person living with dementia has abilities — things they can still do with assistance.
5. Regardless of how effective you are at interacting with a person living with dementia today, this information may help you be more effective in the future. Changing the ways we consider persons living with dementia can help improve the quality of their lives.



Some Questions to Consider

What is dementia?

What does it mean when someone is diagnosed with dementia? Dementia is commonly defined as the loss of mental processing to the point that it interferes with daily activities/function. Dementia is not a disease itself, but a group of symptoms that accompany certain diseases or conditions.

What is Alzheimer's disease?

Alzheimer's is considered a progressive disease. The person progresses through a series of stages, often marked by gradual losses in cognition and memory. This progression is characterized by loss of function and death of nerve cells within the brain. As more brain cells die, more functions are impacted. Alzheimer's is the most common form of dementia.

What is ADRD?

ADRD stands for Alzheimer's disease and related dementias. Below are examples of such related dementias.

- **Lewy Body Dementia** *has a fluctuating course, meaning the person's cognitive and functional abilities vary hour to hour, or day to day. Another sign of Lewy body dementia is that the person may have episodes of hallucinations and signs similar to Parkinson's disease.*
- **Vascular Dementia** *is a general term describing problems with reasoning, planning, judgment, memory, and other thought processes. This form of dementia can result from a stroke, as impaired blood flow to the brain causes damage. The onset of vascular dementia is usually more abrupt than that of Alzheimer's disease.*
- **Frontotemporal Dementia** *first impacts the parts of the brain that control communication and personality.*

ADRD is a broad term to describe a group of uncommon brain disorders that are chronic, progressive, and irreversible with a straight downward trend. The areas of the brain primarily affected are the frontal and temporal lobes, impacting communication and personality.

Cognition, Function, and Developmental Characteristics

Remaining abilities at each stage of dementia can be better understood from the work of Dr. Barry Reisberg, which he called the Theory of Retrogenesis. Dr. Reisberg hypothesized that the progression of Alzheimer's disease through the stages occurs in the reverse order of normal human development. His theory is based on the fact that the parts of the brain developed last are the parts of the brain that Alzheimer's disease impacts first. This theory or concept is also referred to as "First in, Last out."

Given this knowledge of reverse development, a comparison can be made between the person's abilities at a stage of dementia and the corresponding developmental age. This is important because it:

- **Improves awareness as to the amount of assistance the person may need for a task.** *For example, a person performing in Middle Stage dementia may need assistance similar to what a three-year-old child may need to complete a task.*
- **Helps care partners identify remaining abilities of persons living with dementia who are performing at different stages.**
- **Assists in identifying the amount and type of assistance the person may need for a specific activity.**
- **Shifts the focus onto us and how we must adapt and adjust our attitudes, perceptions, and expectations to meet persons living with dementia at their current functioning level.**

Please note: This theory in no way suggests that a person living with dementia should be treated like a child. People living with dementia maintain a sense of dignity and pride, deserving to always be treated with the respect merited by an adult. The person's cognitive functioning level and abilities may be at a given developmental level equivalent of a younger person. We need to adapt our interactions to the appropriate level.

An Abilities-Based Approach

Persons living with dementia maintain the need for a sense of pride and accomplishment. The person will continue to have a sense of well-being and success if caregivers are able to engage the person and assist the person to use their remaining abilities.

Persons living with dementia have remaining abilities throughout all the stages of dementia. However, these stages are often defined by what a person can no longer do instead of what they can still do. This approach does not provide the caregiver with the knowledge to make the most of the person's remaining abilities. If we, as loved ones and caregivers, seek to truly support these individuals, we must change our perceptions and our way of thinking.

Using the Allen Cognitive Disabilities Model developed by Claudia Allen, we can discover what a person can still do at each stage. This perspective allows us to:

- Learn more about the person's remaining abilities.
- Change the environment and/or the activity to match the person's abilities.
- Provide the person with a sense of accomplishment, pride, and motivation.
- Offer activities that they are still capable of engaging with.

You may have heard others say that the persons living with dementia they care for "no longer can care for themselves." We need to focus on what aspects of self-care they can still do with our assistance.

When we interact from an abilities-based perspective, we often discover that those in our care are still capable of communicating with single words, and can convey emotions. With verbal prompts, they can participate in eating, use the bathroom with some assistance, as well as be mobile with the use of a walker.

Progressing Through the Stages

Next, we would like to introduce the stages of dementia from an abilities-based point of view. The remaining abilities for four stages of dementia, along with an estimated corresponding developmental age comparison, are summarized below. An example is provided for each level.

Level 4, or Early Stage dementia

(Developmental age comparison is about 4 to 10–12 years old.)

- a) The person is able to complete a basic activity from the beginning to the end.
- b) The person is goal directed.

An example: *The person is able to complete basic care activities and engage in familiar activities with verbal assistance for quality and accuracy.*

Level 3, or Middle Stage dementia

(Developmental age comparison is about 18 months to 3 years.)

- a) The person is able to use their hands to hold and move objects.
- b) The person is able to follow one-step directions with some assistance.

An example: *The person is able to do steps of basic care activities when provided with verbal prompt and/or demonstration for each step.*

Level 2, or Late Stage dementia

(Developmental age comparison is about 12 to 18 months.)

- a) The person is able to sit, stand, and walk.
- b) The person is able to respond to sensory stimulation, vocalize, say a few words, and engage with another person.

An example: *The person is able to move arms and legs to assist with basic care.*

Level 1, or End Stage dementia

(Developmental age comparison is that of an infant.)

- a) The person is able to respond to sensory stimulation.
- b) The person is able to smile, vocalize, and engage with another person.

An example: *The person may smile and vocalize in response to pleasant sensory experiences.*



Once diagnosed with dementia, a person will progress through these stages, from Early Stage dementia to End Stage dementia. Loved ones and caregivers will need to continue to adapt and adjust accordingly. As of the writing of this booklet, there is no known medication or cure for dementia. As they progress through these stages and change, we must also change.

Changing Our Perceptions of People Living With Dementia

Post-Test

1. **True or False** Dementia is commonly defined as the loss of mental processing to the point that it interferes with daily activities/function.
2. **True or False** Alzheimer's is the most common form of dementia.
3. **True or False** A person living with dementia has remaining abilities at all stages of the progression of the disease.
4. **True or False** If we change our perceptions, we can help a person living with dementia to thrive and not just survive.
5. **True or False** Understanding the developmental level of a person living with dementia can help us adapt how we interact with the person.
6. Reword the following statements to reflect an abilities-based perspective.
 - a. *"My friend cannot even feed himself without my help."*
 - b. *"My mother cannot walk unless she has a walker."*
 - c. *"My dad is no longer really my dad."*

Post-Test Answers

1. **True** Dementia is commonly defined as the loss of mental processing to the point that it interferes with daily activities/function.
2. **True** Alzheimer's is the most common form of dementia.
3. **True** A person living with dementia has remaining abilities at all stages of the progression of the disease.
4. **True** If we change our perceptions, we can help a person living with dementia to thrive and not just survive.
5. **True** Understanding the developmental level of a person living with dementia can help us adapt how we interact with the person.
6. Reword the following statements from an abilities-based perspective.
 - a. *"My friend cannot even feed himself without my help."*
"My friend can eat finger foods with assistance."
 - b. *"My mother cannot walk unless she has a walker."*
"My mother is still mobile when she uses a walker."
 - c. *"My dad is no longer really my dad."*
"My dad is still my dad. He just needs my help more."

Thank you! We hope you found this information helpful.

Please feel free to share this resource with a friend or colleague.

Have questions? We're here for you!

Give us a call at **800.558.8976** or email

info@crisisprevention.com

About Dementia Care Specialists (DCS)

DCS provides state-of-the-art dementia care training, resources and consulting services that help transform staff capabilities and quality of care. We educate, empower, and enrich the lives of these professionals and those in their care living with dementia.

© 2020 CPI. All rights reserved. CPI grants eBook readers permission to share this work with friends and colleagues for noncommercial use, provided they do not remove any trademark, copyright, or other notice. CPI® is a registered trademark of CPI.



FOLLOW US ON   

10850 W. Park Place, Suite 250, Milwaukee, WI 53224 USA
800.558.8976 • 888.758.6048 TTY (Deaf, hard of hearing, or speech impaired)
info@crisisprevention.com • crisisprevention.com

© 2020 CPI. All rights reserved. DCS-DCC-EBK-0038-LT-0920-US