Older Adult Ministries

Christian Church (Disciples of Christ)

# Dementia Caregiver's Support Group

## Part One: The Basics

### Introduction

Alzheimer's disease and other related dementias impact every part of our world. According to the World Health Organization, 55 million people have dementia across the globe. The National Institute on Aging reports 6.2 million are diagnosed with dementia in the US. We are all surrounded by those who are struggling with this reality and are in desperate need of help. Information and community can be a powerful support for these victims of disease and those that care for them. Our goal is to provide practical knowledge and insights that will help caregivers make informed decisions for their loved one and help them better manage the challenges caregivers face.

This four-part facilitator's guide will provide information and reference tools for leading dementia caregiver discussions on multiple topics. It is designed to be used in conjunction with "A Tool Kit for Creating Adult Ministries". The resource links provide access to more detail as needed.

In **Part One: The Basics**, we will explore the following questions.

- What is dementia?
- How is dementia different from Alzheimer's disease?
- Signs and Symptoms
- Causes
- How does dementia differ from normal age-related changes?
- Stages of Alzheimer's disease

Following **Part One: The Basics** we will get into the details that can make a real difference in the lives of people with dementia and their caregivers. The right approach can solve problems and reduce stress. For many, a higher quality of life can be attained than ever thought possible. We will be exploring:

- Part Two - Compassionate Communication
- Part Three - Care Giving Strategies
- Part Four- An overview of Housing and Health Support Options

## What is Dementia?

> https://www.nia.nih.gov/health/what-is-dementia#signs

National Institute on Aging:

> *Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living, such as feeding oneself.*

Key Points

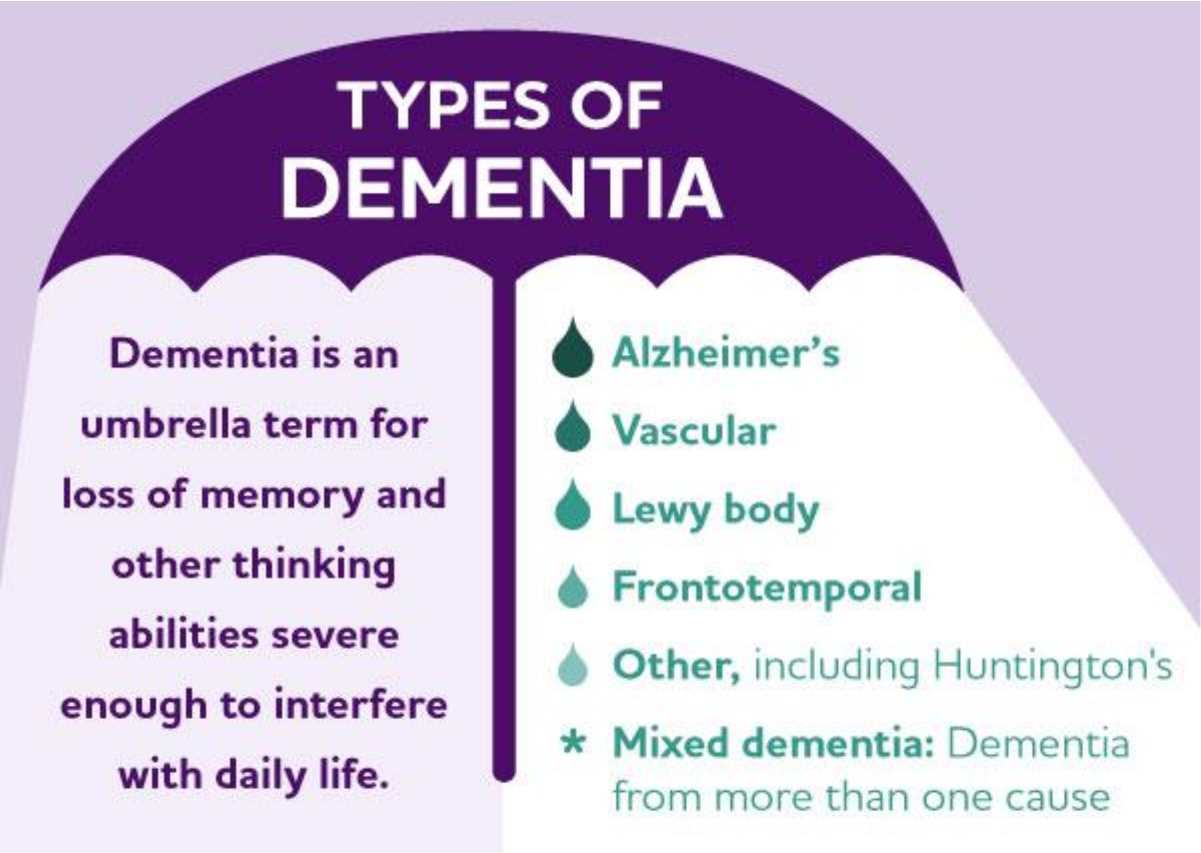
- Dementia is a group of symptoms, not a specific disease.
- Dementia is the loss of cognitive functioning including thinking, remembering, and reasoning.
- The changes in cognitive function must reach the point of interfering with activities of daily living to be defined as dementia.

## What is the difference between dementia and Alzheimer's disease?

> https://www.alz.org/alzheimers-dementia/what-is-dementia

Alzheimer's Association:

> *Dementia is not a single disease; it's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings, and relationships.*
>
> *Alzheimer's disease accounts for 60-80% of cases. Vascular dementia, which occurs because of microscopic bleeding and blood vessel blockage in the brain, is the second most common cause of dementia. Those who experience the brain changes of multiple types of dementia simultaneously have mixed dementia. There are many other conditions that can cause symptoms of dementia, including some that are reversible, such as thyroid problems and vitamin deficiencies.*
>
> *Dementia is often incorrectly referred to as "senility" or "senile dementia," which reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of aging.*



TYPES OF DEMENTIA

Dementia is an umbrella term for loss of memory and other thinking abilities severe enough to interfere with daily life.

- Alzheimer's
- Vascular
- Lewy body
- Frontotemporal
- **Other,** including Huntington's
- * **Mixed dementia:** Dementia from more than one cause

**Key Points**

- Alzheimer's accounts for 60-80% of diseases with dementia symptoms.
- Alzheimer's and other related dementias are caused by abnormal brain changes.
- None of these diseases are a part of normal aging.

## Signs and Symptoms

https://www.nia.nih.gov/health/what-is-dementia#signs

National Institute on Aging:

> *Signs and symptoms of dementia result when once-healthy neurons (nerve cells) in the brain stop working, lose connections with other brain cells, and die. While everyone loses some neurons as they age, people with dementia experience far greater loss.*
> *The signs and symptoms can vary depending on the type and may include:*
>
> - *Experiencing memory loss, poor judgment, and confusion*
> - *Difficulty speaking, understanding and expressing thoughts, or reading and writing*
> - *Wandering and getting lost in a familiar neighborhood*
> - *Trouble handling money responsibly and paying bills*
> - *Repeating questions*
> - *Using unusual words to refer to familiar objects*
> - *Taking longer to complete normal daily tasks*
> - *Losing interest in normal daily activities or events*

- *Hallucinating or experiencing delusions or paranoia*
- *Acting impulsively*
- *Not caring about other people's feelings*
- *Losing balance and problems with movement*

*People with intellectual and developmental disabilities can also develop dementia as they age, and in these cases, recognizing their symptoms can be particularly difficult. It's important to consider a person's current abilities and to monitor for changes over time that could signal dementia.*

## *What causes dementia?*

National Institute on Aging:

*Dementia is the result of changes in certain brain regions that cause neurons (nerve cells) and their connections to stop working properly. Researchers have connected changes in the brain to certain forms of dementia and are investigating why these changes happen in some people but not others. For a small number of people, rare genetic variants that cause dementia have been identified.*

*Although we don't yet know for certain what, if anything, can prevent dementia, in general, leading a healthy lifestyle may help reduce risk factors.*

## What is the difference between normal aging and dementia?

**https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/is-it-getting-older-or-dementia**

Alzheimer's Society UK:

*Is it getting older, or dementia?*
*People often start to forget things more as they get older. Most often this is a normal sign of aging. But for someone with dementia, changes will be different, more serious and will affect their life more.*

*What are the normal signs of aging?*
*As people get older, they are likely to notice some changes in their mental abilities. These could include:*

- *becoming a little more forgetful*
- *taking a bit longer to remember things*
- *getting distracted more easily*
- *finding it harder to do several things at once*

*This may become noticeable particularly from middle age – usually meaning our 40s, 50s and early 60s. Though these changes can be frustrating, they are a natural part of aging. Many people worry that these are early signs of dementia. For most people, this is not the case.*

*How is dementia different from normal aging?*

*Dementia is a group of symptoms. It’s caused by different diseases that* *damage* *the brain.*
*The symptoms of dementia get worse over time and include:*

- *memory loss*
- *confusion and needing help with daily tasks.*
- *problems with language and understanding.*
- *changes in behavior.*

*When a person has dementia, this worsening in mental abilities is much more serious than the normal changes that people experience as they get older.*

## *Memory and new information*

| *Common signs of aging* | *Possible signs of Alzheimer’s disease or vascular dementia* |
|---|---|
| *Forgetting something you were told a while ago* | *Forgetting something you were only recently told. You may ask for the same information repeatedly – for example, 'Are the doors locked?'* |
| *Misplacing things from time to time – for example, your phone, glasses, or the TV remote – but retracing steps to find them* | *Putting objects in unusual places – for example, putting your house keys in the bathroom cabinet* |
| *Taking longer to work out new tasks, such as how to set up and use a new appliance or device* | *Being unable to learn new tasks, like setting up and using a new appliance or device* |

## *Planning and decision making*

| *Common signs of aging* | *Possible signs of Alzheimer’s disease or vascular dementia* |
|---|---|
| *Being a bit slower when planning, but being able to think things through* | *Getting very confused when planning or thinking things through* |
| *Finding it harder to do several tasks at once, but being able to focus on a single task* | *Struggling to stay focused on a single task* |
| *Occasionally making decisions without fully thinking them through* | *Not making informed, careful decisions when dealing with money or looking at risks* |
| *Sometimes making a mistake with a new payment, but being able to manage overall budgets* | *Finding it hard to manage regular payments, like budgets or monthly bills* |

## *Language (speech and conversation)*

| *Common signs of aging* | *Possible signs of Alzheimer’s disease or vascular dementia* |
|---|---|
| *Occasionally struggling to find the right word, but remembering it eventually* | *Having frequent problems finding the right word or regularly referring to objects as 'that thing'* |
| *Needing to concentrate harder to keep up with a conversation, but being able to join in when focused* | *Finding it hard to take part in conversations* |
| *Losing track of the conversation if you’re distracted or if many people are speaking at once* | *Regularly being unable to follow what someone is saying even without distractions* |

## *Orientation (having a sense of time and place)*

| *Common signs of ageing* | *Possible signs of Alzheimer’s disease or vascular dementia* |
|---|---|
| *Getting confused about the day or the week but figuring it out later* | *Losing track of the date, season, or the passage of time* |
| *Getting lost in a place you don’t know well, but being able to figure out where you need to be* | *Getting lost in a place that is familiar or that should be easy to find your way around – for example, a supermarket* |

## ***Mood and behavior***

| *Common signs of aging* | *Possible signs of Alzheimer's disease or vascular dementia* |
|---|---|
| *Sometimes feeling reluctant to join in at work, family, and social meetings* | *Becoming withdrawn and losing interest in work, friends, or hobbies* |
| *Sometimes feeling a bit low or anxious* | *Getting unusually sad, anxious, frightened, or low in confidence* |
| *Becoming irritable when a routine is disrupted, but being able to cope with the change* | *Getting easily upset at home, at work, with friends or in places that usually feel comfortable or familiar* |

Alzheimer's Society UK:

> *These tables list common examples, but everyone's experience of dementia is different, and you know yourself best.*
>
> *Any changes that aren't normal for you should be taken seriously. The changes may not seem big, but if you are struggling with things you used to find easier it's best to speak to your doctor.*

## Stages of Alzheimer's

The stages of Alzheimer’s disease in many ways parallel the disease processes of other related dementia diseases. This makes learning about Alzheimer’s disease useful for those dealing with other related diseases.

Alzheimer’s Association:

https://www.alz.org/alzheimers-dementia/stages

## Overview of disease progression

*Alzheimer’s disease typically progresses slowly in three stages: early, middle, and late (sometimes referred to as mild, moderate, and severe in a medical context). Since Alzheimer’s affects people in different ways, each person may experience dementia symptoms — or progress through the stages — differently.*

*The symptoms of Alzheimer's disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors. Changes in the brain related to Alzheimer's begin years before any signs of the disease. This time period, which can last for years, is referred to as preclinical Alzheimer's disease.*

*The stages below provide an overall idea of how abilities change once symptoms appear and should only be used as a general guide. (Dementia is a general term to describe the symptoms of mental decline that accompany Alzheimer’s and other brain diseases.)*

*The stages are separated into three categories: mild Alzheimer's disease, moderate Alzheimer's disease, and severe Alzheimer's disease. Be aware that it may be difficult to place a person with Alzheimer's in a specific stage as stages may overlap.*

### *Early-stage Alzheimer's (mild)*

*In the early stage of Alzheimer's, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.*

*Symptoms may not be widely apparent at this stage, but family and close friends may take notice and a doctor would be able to identify symptoms using certain diagnostic tools.*

*Common difficulties include:*

- *Coming up with the right word or name.*
- *Remembering names when introduced to new people.*
- *Having difficulty performing tasks in social or work settings.*
- *Forgetting material that was just read.*
- *Losing or misplacing a valuable object.*
- *Experiencing increased trouble with planning or organizing*

*You can live well. During the early stage, it's possible for people with dementia to live well by taking control of their health and wellness, and focusing their energy on aspects of their life that are most meaningful to them. In addition, this is the ideal time to put legal, financial, and end-of-life plans in place because the person with dementia will be able to participate in decision-making.*

### *Middle-stage Alzheimer's (moderate)*

*Middle-stage Alzheimer's is typically the longest stage and can last for many years. As the disease progresses, the person with Alzheimer's will require a greater level of care.*

*During the middle stage of Alzheimer's, the dementia symptoms are more pronounced. The person may confuse words, get frustrated or angry, and act in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can also make it difficult for the person to express thoughts and perform routine tasks without assistance.*

*Symptoms, which vary from person to person, may include:*

- *Being forgetful of events or personal history.*
- *Feeling moody or withdrawn, especially in socially or mentally challenging situations.*
- *Being unable to recall information about themselves like their address or telephone number, and the high school or college they attended.*
- *Experiencing confusion about where they are or what day it is.*
- *Requiring help choosing proper clothing for the season or the occasion.*
- *Having trouble controlling their bladder and bowels.*
- *Experiencing changes in sleep patterns, such as sleeping during the day and becoming restless at night.*
- *Showing an increased tendency to wander and become lost.*
- *Demonstrating personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding.*

*In the middle stage, the person living with Alzheimer's can still participate in daily activities with assistance. It's important to find out what the person can still do or find ways to simplify tasks. As the need for more intensive care increases, caregivers may want to consider respite care or an adult day center so they can have a temporary break from caregiving while the person living with Alzheimer's continues to receive care in a safe environment.*

### *Late-stage Alzheimer's (severe)*

> *In the final stage of the disease, dementia symptoms are severe. Individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, significant personality changes may take place and individuals need extensive care.*
>
> *At this stage, individuals may:*
>
> - *Require around-the-clock assistance with daily personal care.*
> - *Lose awareness of recent experiences as well as of their surroundings.*
> - *Experience changes in physical abilities, including walking, sitting and, eventually, swallowing.*
> - *Have difficulty communicating.*
> - *Become vulnerable to infections, especially pneumonia.*
>
> *The person living with Alzheimer's may not be able to initiate engagement as much during the late stage, but he or she can still benefit from interaction in ways that are appropriate, like listening to relaxing music or receiving reassurance through gentle touch. During this stage, caregivers may want to use support services, such as hospice care, which focus on providing comfort and dignity at the end of life. Hospice can be of great benefit to people in the final stages of Alzheimer's and other dementias and their families.*

This concludes **Part One: The Basics**.

In Part Two - Compassionate Communication, we will explore the fundamental role of communication in achieving quality of life and maintaining relationships with loved ones afflicted with dementia.

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## Dementia Caregiver's Support Group

## Part 2: Compassionate Communication

### Introduction

Communication, the process of trying to achieve a shared reality with another person, is often a less than perfect process under normal conditions.  Add the complications of dementia, loss of hearing, and loss of visual acuity and communication becomes extraordinarily difficult.

When interacting with a person with dementia, it is critical to understand we must go into their world on their terms. The disease is taking away their ability to understand and communicate the way they used to. Let's review some expert content to help us learn to communicate with love and compassion.

What is it like to have dementia? Let's work on our perspective . . .

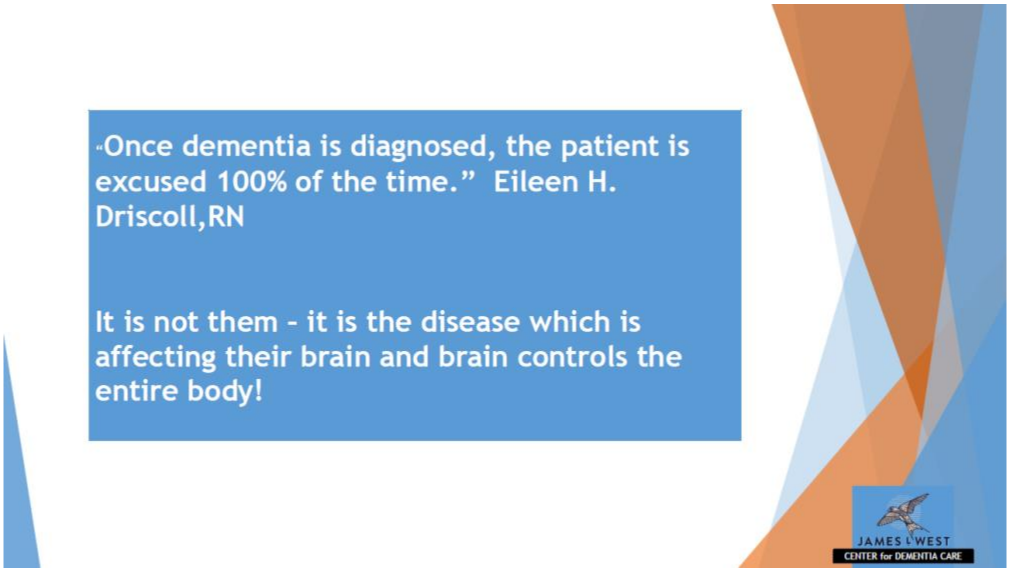
> From The Alzheimer's Society, San Diego California
>
> *"You can't control memory loss – only your reaction to it.*
>
> *For people with dementia, their disability is memory loss. Asking them to remember is like asking a blind person to see. (Common questions like "Did you take your pills?" or "What did you do today?" are the equivalent of asking them to remember something.) A loss of this magnitude reduces the capacity to reason. Expecting them to be reasonable or to accept your conclusion is unrealistic. Don't correct, contradict, blame, or insist. Reminders are rarely kind. They tell a person how disabled they are – over and over again.*
>
> *People living with dementia say and do normal things for someone with memory impairment. If they were deliberately trying to exasperate you, they would have a different diagnosis.* ***Forgive them…always.*** *For example, your wife isn't purposely hiding your favorite pair of shoes. She thinks she's protecting them by putting them in a safe place…and then forgets."*

https://www.alzsd.org/dos-and-donts-of-compassionate-communication-dementia/

## Key Points

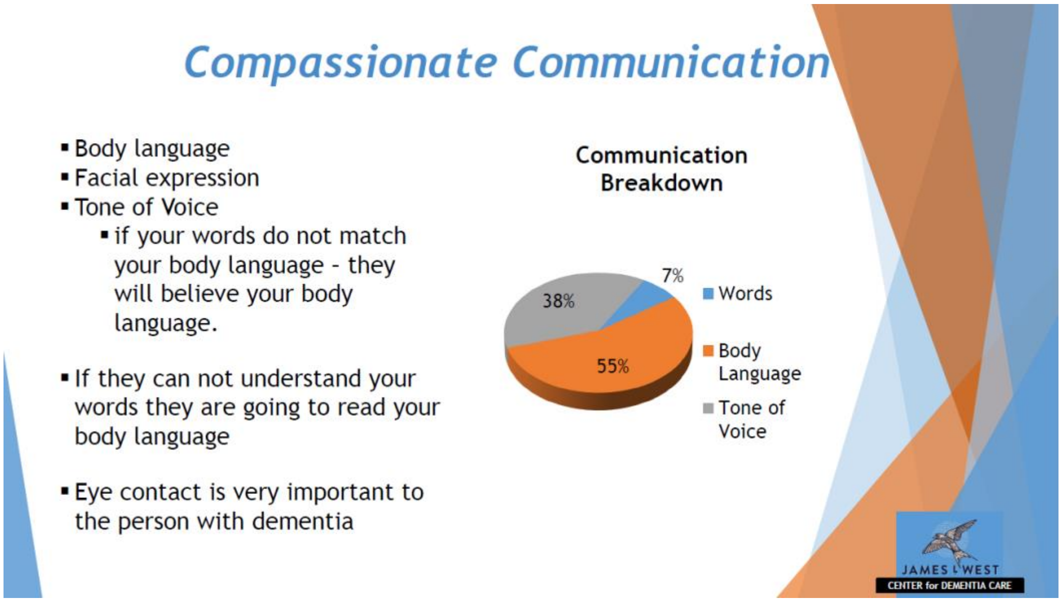
- We must go into the world of a person with dementia. They cannot come into our world.
- Our being “Right” seldom works to improve a situation but can often make it worse.
- Common communication may be hurtful.
- All behaviors have a reason. It may take a while for us to understand them.
- It’s not personal…but it sure may feel like it.

The James L West Center for Dementia Care in Fort Worth Texas provides the following graphics:



“Once dementia is diagnosed, the patient is excused 100% of the time.” Eileen H. Driscoll,RN

It is not them - it is the disease which is affecting their brain and brain controls the entire body!



Compassionate Communication

- Body language
- Facial expression
- Tone of Voice
  - if your words do not match your body language - they will believe your body language.
- If they can not understand your words they are going to read your body language
- Eye contact is very important to the person with dementia

## Key Points

- Compassionate Communication is multifaceted
- Effective Compassionate Communication can be learned and developed

The Alzheimer's Association has the following overview of communication difficulties and strategies for each of the stages of dementia.

## Changes in communication

Changes in the ability to communicate can vary and are based on the person and where he or she is in the disease process. Problems you can expect to see throughout the progression of the disease include:

- Difficulty finding the right words
- Using familiar words repeatedly
- Describing familiar objects rather than calling them by name
- Easily losing a train of thought
- Difficulty organizing words logically
- Reverting to speaking a native language
- Speaking less often
- Relying on gestures more than speaking

## Communication in the early stage

In the early stage of Alzheimer's disease, sometimes referred to as mild Alzheimer's in a medical context, an individual is still able to participate in meaningful conversation and engage in social activities. However, he or she may repeat stories, feel overwhelmed by excessive stimulation, or have difficulty finding the right word. Tips for successful communication:

- Don't make assumptions about a person's ability to communicate because of an Alzheimer's diagnosis. The disease affects each person differently.
- Don't exclude the person with the disease from conversations.
- Speak directly to the person rather than to his or her caregiver or companion.
- Take time to listen to the person express his or her thoughts, feelings, and needs.
- Give the person time to respond. Don't interrupt unless help is requested.
- Ask what the person is still comfortable doing and what he or she may need help with.

- Discuss which method of communication is most comfortable. This could include face-to-face conversation, email, or phone calls.
- It's OK to laugh. Sometimes humor lightens the mood and makes communication easier.
- Don't pull away; your honesty, friendship and support are important to the person.

## Communication in the middle stage

The middle stage of Alzheimer's, sometimes referred to as moderate Alzheimer's, is typically the longest and can last for many years. As the disease progresses, the person will have greater difficulty communicating and will require more direct care. Tips for successful communication:

- Engage the person in one-on-one conversation in a quiet space that has minimal distractions.
- Speak slowly and clearly.
- Maintain eye contact. It shows you care about what he or she is saying.
- Give the person plenty of time to respond so he or she can think about what to say.
- Be patient and offer reassurance. It may encourage the person to explain his or her thoughts.
- Ask one question at a time.
- Ask yes or no questions. For example, "Would you like some coffee?" rather than "What would you like to drink?"
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what the person says. Repeat what was said to clarify.
- Avoid arguing. If the person says something you don't agree with, let it be.
- Offer clear, step-by-step instructions for tasks. Lengthy requests may be overwhelming.
- Give visual cues. Demonstrate a task to encourage participation.
- Written notes can be helpful when spoken words seem confusing.

## Communication in the late stage

The late stage of Alzheimer's disease, sometimes referred to as severe Alzheimer's, may last from several weeks to several years. As the disease advances, the person with Alzheimer's may rely on nonverbal communication, such as facial expressions or vocal sounds. Around-the-clock care is usually required in this stage. Tips for successful communication:

- Approach the person from the front and identify yourself.

- Encourage nonverbal communication. If you don't understand what the person is trying to say, ask him or her to point or gesture.

- Use touch, sights, sounds, smells, and tastes as a form of communication with the person.

- Consider the feelings behind words or sounds. Sometimes the emotions being expressed are more important than what's being said.

- Treat the person with dignity and respect. Avoid talking down to the person or as if he or she isn't there.

- It's OK if you don't know what to say; your presence and friendship are most important.

https://www.alz.org/help-support/caregiving/daily-care/communications

From the Alzheimer's Society, San Diego California:

**Here are some basic Do's when it comes to communication with someone with dementia:**

- Give short, one sentence explanations.
- Allow plenty of time for comprehension, and then triple it.
- Repeat instructions or sentences exactly the same way.
- Avoid insistence. Try again later.
- Agree with them or distract them to a different subject or activity.
- Accept the blame when something's wrong (even if it's fantasy).
- Leave the room, if necessary, to avoid confrontations.
- Respond to the feelings rather than the words.
- Be patient and cheerful and reassuring. Do go with the flow.
- Practice 100% forgiveness. Memory loss progresses daily.

**Here are some Don'ts:**

- Don't reason.
- Don't argue.
- Don't confront.
- Don't remind them they forget.
- Don't question recent memory.
- Don't take it personally.

We've put together some specific examples of good and bad communication below, keeping these do's and don'ts in mind. We also have plenty of **tip sheets** in various languages regarding more aspects of dementia.

1) **"What doctor's appointment? There's nothing wrong with me."**
   Don't: (reason) "You've been seeing the doctor every three months for the last two

years. It’s written on the calendar, and I told you about it yesterday and this morning.”
DO: (short explanation) “It’s just a regular checkup.”
(accept blame) “I’m sorry if I forgot to tell you.”

2) **“I didn’t write this check for $500. Someone at the bank is forging my signature.”**
Don’t: (argue) “What? Don’t be silly! The bank wouldn’t be forging your signature.”
DO: (respond to feelings) “That’s a scary thought.”
(reassure) “I’ll make sure they don’t do that.”
(distract) “Would you help me fold the towels?”
3) **“Nobody’s going to make decisions for me. You can go now…and don’t come back!”**
Don’t: (confront) “I’m not going anywhere and you can’t remember enough to make your own decisions.”
DO: (accept blame or respond to feelings) “I’m sorry this is a tough time.”
(reassure) “I love you and we’re going to get through this together.”
(distract) “You know what? Don has a new job. He’s really excited about it.”
4) **“Joe hasn’t called for a long time. I hope he’s okay.”**
Don’t: (remind) “Joe called yesterday, and you talked with him for 15 minutes.”
DO: (reassure) “You really like talking with him, don’t you?”
(distract) “Let’s call him when we get back from our walk.”
5) **“Hello, Mary. I see you’ve brought a friend with you.”**
Don’t: (question memory) “Hi Mom. You remember Eric, don’t you? What did you do today?”
DO: (short explanation) “Hi Mom. You look wonderful! This is Eric. We work together.”
6) **“Who are you? Where’s my husband?”**
Don’t: (take it personally) “What do you mean – who’s your husband?” I am!”
DO: (go with the flow, reassure) “He’ll be here for dinner.”
(distract) “How about some milk and cookies?… Would you like chocolate chip or oatmeal?”
7) **“I’m going to the store for a newspaper.”**
Don’t: (repeat differently) “Please put your shoes on.”…You’ll need to put your shoes on.”
DO: (repeat exactly) “Please put your shoes on.”… “Please put your shoes on.”
8) **“I don’t want to eat this! I hate chicken.”**
Don’t: (respond negatively) “You just told me you wanted chicken. I’m not making you anything else, so you better eat it!”
Do: (accept blame) “I’m so sorry, I forgot. I was in such a rush that it slipped my mind. (respond positively) Let me see what else we have available.” Leave the room and try again.

https://www.alzsd.org/dos-and-donts-of-compassionate-communication-dementia/

## Conclusion

Better Communication- Better Life!

Our expert sources have identified challenges and strategies for communication with persons with dementia. There are similarities and interesting variations in approaches. This is helpful because every person with dementia remains an individual and will go through the disease in their own way. As we become better communicators, the role of caregiving becomes more manageable, and the quality of relationships can significantly improve.

# Dementia Caregiver's Support Group

## Part 2: Strategies for Dementia Caregivers

### Introduction

We all want to be the best caregivers we can be. Anyone who has ever been a caregiver knows how difficult the role is. We are going to explore strategies and best practices that can help us be successful in very challenging situations. Sources used to gather this information, include two organizations that I have been privileged to be associated with. Two other organizations will be cited from their publicly published materials.

The following two organizations have been nationally recognized for excellence in creating programs that have greatly improved the quality of life for those diagnosed with dementia and supporting the families and friend that love and care for them.
They come from the dementia programing found at:

- Juliette Fowler Communities, Dallas Texas. I'm Still Here Center for Excellence
- The Mildred and Shirley L. Garrison Geriatric Education and Care Center, Texas Tech University, Lubbock Texas

These approaches are not exclusive to these organizations, but they are the ones I have personally been involved with and have seen these best practices in action. These two organizations have been recognized nationally for innovation, excellence in programing, and extraordinary outcomes.

It is my sincere hope this will help you on your journey as a caregiver.
Ken Carpenter, MS, LNHA

### We are Social Beings

People with dementia have the same needs we do. Their disease makes it more difficult to fulfill these needs and requires unique strategies on our part to help them. These needs include human connections, negotiating social situations, and meeting expectations. To fail socially is painful for human beings. Do you remember your most embarrassing moment, the one you never talk about? Even after years have passed you can feel increasingly uncomfortable as you dwell on that moment, perhaps even blushing in shame. Dementia does not remove this sensitivity to social failure. An important goal as a caregiver is to protect our loved one's dignity and sense of social wellbeing. To fail this goal will make all other goals more difficult to achieve.

People with dementia cannot come into our world. We must go with them into their world. The better we understand what it might be like to have dementia, the more effective we will be in connecting with them, protecting their sense of self-worth, and achieve a high quality of life.

## Timing and Expectations

A person with dementia perceives time differently and the disease slows their response time. At Juliette Fowler Communities we often use this demonstration during caregiver seminars.
Quick exercise:

> *"I need two volunteers.*
>
> *Thank you, Nicole, and Lori,*
>
> *Nicole, please ask Lori a question.*
>
> *But!*
>
> *Lori, please do not answer until I tell you to."*
> *(Wait ten full seconds before telling Lori to respond)*

***Ten seconds between a question and an answer response is a typical response time for someone with dementia. Many people require much more time to process a question.***

Ten seconds is an exceedingly long and uncomfortable amount of time for people without dementia to wait for a response in a conversation. Let us consider the perspective of someone with dementia. Imagine if you were not allowed an opportunity to respond to a question. What if you were asked a question and before you could answer, you were dismissed?

It is important for us to realize the basic challenge of processing time in connecting with a person with dementia. To not allow sufficient time to respond is hurtful and diminishes the person. We are telling them they are inadequate and unimportant. They may become angry and strike out or they may withdraw from us. Patience is a fundamental requirement for successful caregivers.

## Choices and Decisions

People with dementia experience a long series of losses. We want to protect their sense of autonomy and sense of worth by letting them make decisions. At the same time, we do not want to overwhelm them with a question they may struggle to answer.

***It is best to present limited options and avoid open-ended questions.***
Instead of asking "what do you want to wear," ask them "Do you want to wear the blue dress or the red dress.

At mealtime, rather than asking "What do you want to eat?" and "what do you want to drink?"

Try asking, “Do you want a chicken sandwich, or a ham sandwich? “ “Do you want iced tea or lemonade?”

## “Telling the Truth” vs “Shared Reality”

One of my favorite definitions of communication is the achievement of a shared reality between people. Achieving a “shared reality” is often difficult for most people. It gets more complicated when dealing with someone with dementia. We have already learned we have to go into their world, that they can no longer fully come into ours.

What do we do when our loved one is unable to share the reality of various facts? What do we do when our mother believes her deceased husband is still alive and she is anxious to see him?

Most of us were raised to tell the truth. What happens when we tell “the truth”?

Mom: “Where is your dad?”

You: “Mom, Dad died 7 years ago”

If you do achieve a “Shared Reality,” and the information that Dad is dead is accepted as truth, Mom goes through the shock of the terrible news. She goes through the pain and grieving again, just like 7 years ago.

Have you ever awakened the day after the death of a loved one and for a moment forgot what happened? That devastating moment of realization is as raw as the first time you received the news.

The person with dementia that is repeatedly “told the truth, “ is destined to relive their most painful moments repeatedly. No one wants that to happen.

What if you do not achieve a “shared reality” and Mom is hurt and angry that you would make up such a terrible lie? The loss of trust can undermine all your efforts to be a good caregiver.

Developing and protecting trust is a fundamental priority for any caregiver.
So, what do you do when Mom wants to see her deceased husband?
Three valuable tools! These concepts are effective in many situations.

- **Validation—**acknowledging the person’s thoughts and feelings. When we are understood, we feel better and tend to be less resistant to new ideas and information. This is especially true for people with dementia. (Please note, this is definition is not the same as the concept of Validation Therapy. Validation Therapy is closely associated with Naiomi Feil and is a clinical approach used by some advanced dementia practitioners)

- **Redirection**—Redirection is a technique that can help calm people with dementia by shifting their attention away from negative feelings and behaviors. Initiating a pleasant topic or an activity can attract the loved one away from what is difficult and disruptive.
- ***"The Greatest Loss from Having Dementia Is the Loss of Memory***  
  ***Sometimes the Best Tool to Deal with Dementia Is the Loss of Memory"***  
  *Kena Philips, Assistant Administrator, Garrison Center.*

What does that mean *"*Sometimes the Best Tool to Deal with Dementia Is the Loss of Memory"? When dealing with a person with dementia in a difficult situation, breaking their focus for a few minutes may allow an opportunity to move them past the difficult ideation and to go to a more pleasant and manageable state of mind. Understanding this "loss of memory tool" can improve your success when redirecting your loved one.

Let's go back to Mom waiting for her husband to be there. Consider responses like these.

"Mom, I know you miss Dad; I want to see Dad too, I miss him when he is not here Dad can't come right now, but I know he would if he could" (Validation)."

I'm going to have a cup of coffee and a cookie before we watch Jeopardy, would you like coffee and cookies too?" (Redirection) Hopefully, mom's focus will shift from waiting for her husband to having an enjoyable time watching her favorite game show.

Using redirection and validation in the context of loss of short-term memory can make the task of caregiving much more pleasant and effective, helping our loved ones have a higher quality of life.

The following is from a British organization, *Contented Dementia Trust:*  
**Three Golden Rules**

1. **Don't ask direct questions**
2. **Listen to the expert – the person with dementia – and learn from them**
3. **Don't contradict**

These **Three Golden Rules** run contrary to commonsense communication styles which are taken for granted when dementia is not an issue.  
The **Three Golden Rules** are counter-intuitive and those of us without dementia need to develop this entirely new set of communication skills.

Read our simple examples and explore the difference you can make to someone with dementia:

**1. Don't ask direct questions**  
Avoid asking any direct question that requires the person with dementia to search for factual information that may not be stored in their album. They are already aware of their disability.

Asking them to search for facts they may not have will merely increase this awareness, causing them unnecessary distress and potential trauma…

**2. Listen to the expert (the person with dementia) and learn from them**
Listen to the questions the person with dementia is asking and consider very carefully what the best answer might be from their perspective rather than your own. For people with dementia, feelings are more important than facts. It is crucial that the information they receive generates good feelings for them…
We owe it to the person with dementia to avoid leaving them with anxieties that they cannot, only moments later, explain.

So, we must search for the information and the language that is most acceptable to them. Once we have found the best answer to their most frequent question, this form of words should be used consistently by everyone coming into contact with the person…

**Nowadays I try and say something like 'I expect you're right', and straight away the problem that was brewing just seems to vanish.** (Validation)

**3. Don't contradict:**
Do not argue with the person with dementia about which page or which photograph they are choosing to use in their album. They are increasingly likely to use intact memories from their pre-dementia past, in order to understand what is happening around them in the present. The rest of us need to avoid disturbing the sense they are making and start where they are at. We need to take careful note of the language they use, so that we can follow them, rather than expecting them to follow us…

https://contenteddementiatrust.org/specal-method/three-golden-rules/

The following blog was originally posted by Marie Marley on *Huffington Post*:

**5 Things to Never Say to a Person with Alzheimer's**

Yesterday afternoon, I walked into the spacious room belonging to Mary, a woman with dementia who has few visitors and with whom I've volunteered to spend a little time every week. I greeted her, complimented her on her beautiful turquoise sweater, and shook her hand.

Then I sat down at her little table that was overflowing with books, photographs, the newspaper and other items she wants to keep close at hand. I started off by picking up a small framed photo of Mary with her husband and three children -- two sons and a daughter.

"Tell me about your daughter," I said, using an open-ended question because they have no right or wrong answers. That's a tip I picked up from The Best Friends Approach to Alzheimer's Care by Virginia Bell and David Troxell.

"Oh, her name is Connie," she told me. "She has four children -- two boys and two girls."

She continued, giving me several details about Connie and her family. I then picked up a photograph of Mary and her twin sister, Bernice, and she told me about how they took piano lessons together when they were children. After a few minutes, I asked her if her daughter ever played a musical instrument.

"I don't have a daughter," she said matter-of-factly.

"Oh," I countered, picking up the family photo again and holding it out for her to see. "You just told me you have a daughter. Here she is."

Mary's face fell and she said very quietly, "I guess I do have a daughter."

I immediately felt sorry for her embarrassment and was disgusted with myself for having pointed out her mistake. I realized I'd just broken one of the cardinal rules for interacting with a person who has dementia. I'd just read it in The Best Friend's Approach that very morning: "Let the person save face."

## Relating to a person with Alzheimer's

When relating there are many guidelines to follow. I'm going to discuss five of the most basic ones:

**Don't Tell Them They're Wrong About Something**: To let the person save face, it's best not to contradict or correct them if they say something wrong. There's no good reason to do that. If they're alert enough, they'll realize they made a mistake and feel bad about it. Even if they don't understand their error, correcting them may embarrass or be otherwise unpleasant for them.

**Don't Argue With the Person:** It's never a good idea to argue with a person who has dementia. First of all, you can't win. And second, it will probably upset them or even make them angry. I learned a long time ago, when caring for my beloved Romanian soul mate, Ed, the best thing to do is simply change the subject -- preferably to something pleasant that will immediately catch their attention. That way, they'll likely forget all about the disagreement.

**Don't Ask if They Remember Something:** When talking with a person who has Alzheimer's, it's so tempting to ask them if they remember some person or event. "What did you have for lunch?" "What did you do this morning?" "Do you remember that we had candy bars when I visited last week?" "This is David. Do you remember him?" Of course they don't remember. Otherwise, they wouldn't have a diagnosis of dementia. It could embarrass or frustrate them if they don't remember. It's better to say, "I remember that we had candy the last time I was here. It was delicious."

**Don't Remind the Person that a Loved One Is Dead**: It's not uncommon for people with dementia to believe their deceased spouse, parent or other loved one is still alive. They may be confused or feel hurt that the person doesn't come to visit. If you inform them that the person is dead, they might not believe it and become angry with you. If they do believe you they'll probably be very upset by the news. What's more, they're likely to soon forget what you said and go back to believing their loved one is still alive. An exception to this guideline is if they ask you if the person is gone. Then it's wise to give them an honest answer, even if they will soon forget it, and then go on to some other topic.

**Don't Bring up Other Topics That May Upset Them:** There's no reason to bring up topics you know may upset your loved one. If you don't see eye-to eye on politics, for example, don't even bring it up. It may just kindle an argument, which goes against the second guideline above. You won't prevail and it's just likely to cause them anger and/or frustration.

So, there you go. A few guidelines for visiting. I hope these will be helpful to you in visiting your loved one and enriching for the time you have together.

www.usagainstalzheimers.org/blog/5-things-never-say-person-alzheimers

## Conclusion

I hope this presentation of fundamental strategies and other takes on the subject will help you with the precious task of caring for your loved one with dementia. The role of caregiver is never easy. These basic principles can make a significant difference in the outcomes of your work. You are running a marathon, not a 50-yard dash.

Always remember to take care of yourself. Find friends and people of similar circumstances to share successes and failures with. Find support systems so you can get a break. Perhaps a family member, a part time caregiver, or an adult daycare provider.

Pause long enough to see past how much has been lost. Create new moments. Look and see that the person is still there: their spark of life, and the sparkle in their eye.