

The Many Hats of Caregiving

**Tools for Communication
and Tackling Challenging
Care Situations**

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Welcome!

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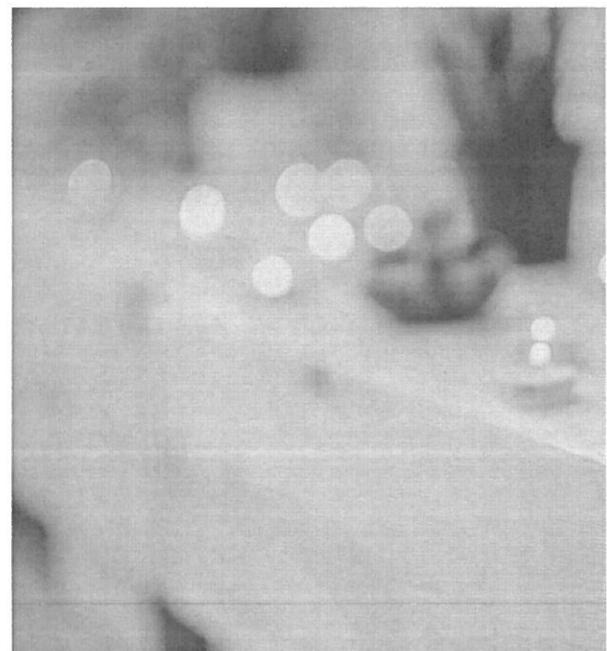
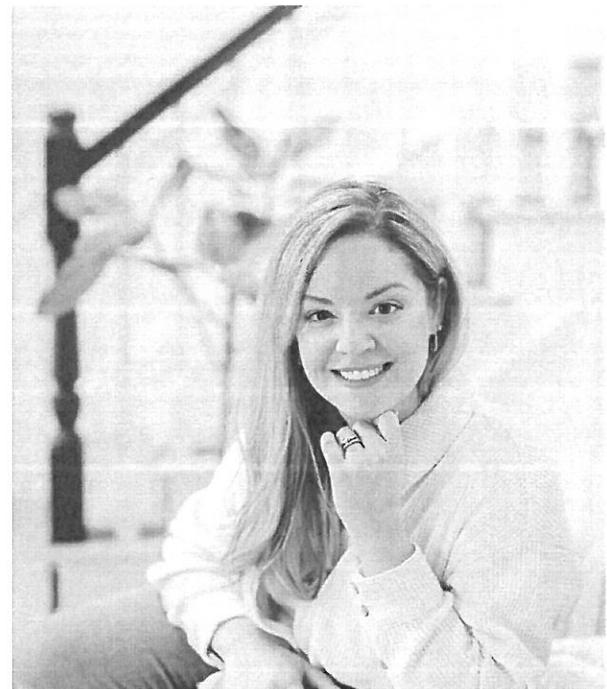
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I appreciate your support:

IF YOU FEEL THAT OTHERS MAY BENEFIT FROM THIS RESOURCE OR MY DEMENTIA NAVIGATION SERVICES, THEN PLEASE DIRECT THEM TO ME OR MY WEBSITE:

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CONTENT OUTLINE

1

DEMENTIA - MORE THAN JUST MEMORY LOSS

Understanding the connection with executive function decline, normal aging, Mild Cognitive Impairment (MCI), and dementia

2

WHAT IS SUNDOWNING

Understanding Sundowning and potential triggers

3

PUT YOUR IMPROV HAT ON

Tackling communicating with your loved one when things aren't making sense. Tips for responding to questions such as, "Where is my mom?" or "I need to go home!"

4

PUT YOUR DETECTIVE HAT ON

Understand signs of agitation when your loved one can no longer communicate what is wrong through words - Your own detective checklist

5

ADDITIONAL RESOURCES & INFORMATION

Information about additional free resources that The Memory Compass provides, along with our paid courses and service offerings.

Normal Aging vs Signs of a More Advanced Cognitive Decline

The information provided can be used as a quick reference tool for what is considered to be characteristics of normal aging, Mild Cognitive Impairment, and signs of a more advanced cognitive decline.

Normal Aging

- Changes in ability to multi-task
- Slowing of thinking speed
- Occasional errors in complex problem solving such as balancing a checkbook
- Simple forgetfulness such as placement of keys or cell phone but the ability to retrace steps
- Delay or slowing of recall of dates, names, or events but able to recall later
- Requiring occasional help with technology or appliances but able to learn
- Symptoms may only be noticed by the individual

Mild Cognitive Impairment

- Still able to manage their day to day lives but needs some supports in place
- Overwhelm (planning, organizing)
- Losing items
- Forgetting meetings/appointments
- May start to isolate and feel embarrassed
- Changes may be subtle but this is still more than normal aging and easily viewed as normal aging due to misconceptions – it is actually early stage of memory loss
- The individual as well as others notice this change

More Advanced Cognitive Decline

- Difficulty with remembering to take medications
- Difficulty with finances
- New onset of changes in behavior or mood
- Difficulty with remembering appointments or events
- Getting lost going to familiar places
- Difficulty with word finding
- Difficulty with sequencing through familiar tasks at work, home, or in the community
- Forgetting familiar names and familiar places
- Difficulty with the transition of environments
- Withdrawal from social events
- Difficulty with keeping up with self-care/hygiene
- Repetition of statements
- Forgetting to eat meals
- Weight loss
- Frequent falls
- Resistance to bathing
- Refusing to accept assistance with care

A screening tool for family members and care partners is the AD8 Dementia Screening Interview

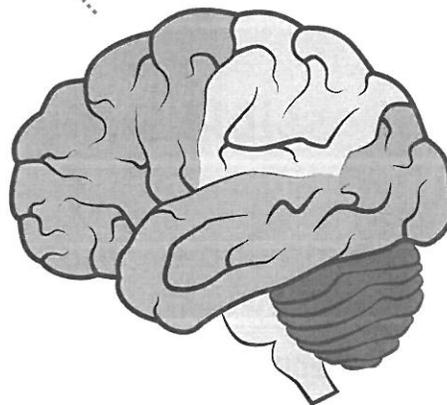
<https://www.alz.org/media/Documents/ad8-dementia-screening.pdf>

Frontal Lobe & Executive Function

At The Memory Compass, we believe there needs to be more awareness of how dementia is more than just memory loss. Dementia also results in changes in executive function skills that will impact the carryover of everyday tasks, including our instrumental activities of daily living (IADLs) and activities of daily living (ADLs). Our executive function skills are primarily housed in the prefrontal cortex of the frontal lobe of our brain. Outlined below are examples of executive functions:

Frontal Lobe

- **Problem Solving**
- **Judgement**
- **Inhibition of Behavior**
- **Planning**
- **Anticipation**
- **Speaking**
- **Emotional Expression**
- **Awareness of Abilities**
- **Self-monitoring**
- **Motor planning**
- **Personality**
- **Sexual behavior**
- **Behavior control**
- **Limitations**
- **Organizations**
- **Attention**
- **Concentration**
- **Mental flexibility**
- **Initiation**



Executive functioning is goal-directed behavior. For example, it is our motivation, planning, initiation, and sequencing to complete tasks such as:

- Getting the mail
- Organizing a closet
- Planning an event like a party or trip
- Taking medications
- Managing finances
- Preparing a light meal or snack
- Going into the bathroom and toileting
- Changing clothing
- Doing daily exercises

WHAT IS SUNDOWNING?

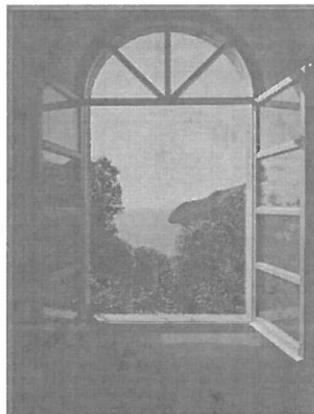
Increased confusion that people living with dementia may experience during the period of late afternoon through the night. Sundowning may present as:

- Increased confusion
- Anxiety or Agitation
- Difficulty Sleeping
- Pacing or Wandering
- Disorientation

*Source: Alzheimer's Association

Possible Sundowning Triggers

- Overstimulation and exhaustion fatigue from the day
- Navigating new or unfamiliar environments
- Mixed up "internal clock" of day/night
- Poor lighting or poor environmental design (shadows, "holes", etc)
- Stress and body language from those around them
- Dreaming and disorientation from reality vs dream



*Source: Alzheimer's Association

Put Your Improv Hat On



Tackling How to Communicate With Your Loved One When Things Aren't Making Sense

Common comments I hear from my clients:

"My loved one is in denial of their deficits."

"My loved one cannot be reasoned with. They believe something happened that didn't happen!"

Dementia impacts our frontal lobe function. Our frontal lobe is responsible for our ability to reason, our mood, our behavior, and our ability to empathize. If your loved one is demonstrating poor awareness of acknowledging their diagnosis or recognizing their cognitive decline changes, they are likely experiencing **anosognosia**, which is the lack of ability to perceive the realities of one's own condition as a result of changes in the brain. It is not the same as denial, which is awareness of changes happening due to a condition but refusal to accept the changes.

HELPFUL TERMS & DEFINITIONS

- Anosognosia: the lack of ability to perceive the realities of one's own condition as a result of changes taking place in the brain.
- Denial: awareness of changes happening due to a condition, but refusal to accept the changes.
- Hallucination: hearing, seeing, smelling, and/or feeling things that are not really there.
- Delusion: False beliefs that the person thinks are real that are not real. For example, someone stealing something from them.
- Paranoia: a type of delusion in which a person may believe - without a good reason - that others are mean, lying, unfair, or "out to get me." - a person may experience being suspicious, fearful, or jealous of others

The Leap Method

It can be incredibly challenging for care partners to navigate a loved one living with dementia, not only demonstrating memory loss (i.e., forgetting to take medications, pay bills, safely operate a vehicle, or safely manage cooking) but also navigating the challenge of their loved one presenting with lack of awareness that these cognitive challenges exist due to **anosognosia**. Some loved ones living with dementia are entirely convinced that they are still healthy and able to manage the day-to-day just as before their diagnosis. Anosognosia is difficult for your loved one but can also impact relationships with family and friends, care partners, and companions.

The LEAP method is a tool to help you better communicate with your loved one rather than trying to reason with them. It involves actively listening to their point of view and taking a more thoughtful communication approach to their cognitive challenges.

Listen: Let your loved one know you hear what they are saying

Empathize: The feelings they are having are very real to them. Listen to their reasoning, beliefs, and feelings to help them feel understood. This may help decrease feelings of defensiveness

Agree: Avoid offering your opinion and try to find common ground to focus on

Partner: You may not agree on the problem, but you can build trust with your loved one to try to move on to a solution together

Care Partner Communication Tips

Helpful Dementia Care Tips For Repetition and Challenging Questions:

- Instead of focusing on the words themselves, listen for the emotion behind the words. Whatever your loved one is expressing, it is very real and upsetting for them. Focus on the emotion and how to comfort their emotion.
- When your loved one is repeating their statements, they typically look to you for comfort. They aren't trying to give you a hard time. They are having a hard time.
- Pause to take a second to think about your own reaction to their emotion. Will your reaction be productive to the situation? Remember, your loved one no longer has the same filter that you do.
- You will not provide your loved one comfort by telling them to "calm down" "we just talked about this" or "I already told you, remember?" You especially do not want to tell someone that something is "all in their head" when what they are feeling is very real to them. We need to put on our improv hat and acknowledge their reality.
- Provide an answer even if the answer is something that you have said over and over. Try to keep calm and provide the answer calmly. If you need to step out of the room afterward to compose yourself, that is ok.
- If your loved one is able to attend to notes and comprehend written language then providing reminders by showing them a notecard, planner, or dry-erase board with the answer to their repeated question written on it may be helpful.
- Redirect by providing a purposeful activity such as folding clothes, cleaning down the counters, or vacuuming. If things are already clean that is ok! Your goal is to provide your loved one with a calm purpose-driven activity.
- Sometimes no matter what we do these questions do not go away. In this situation, we can only control how we are going to react to them.

Challenging Communication Situation Examples

The following examples are gathered from my own personal ten years of experience working as a professional within the dementia care space as a speech-language pathologist and now as a dementia navigation coach and consultant. I have included examples of challenging communication situations followed by tips on communication approaches to avoid and helpful communication approaches to try instead. Sometimes, we must put our improv hat on and meet our loved ones where they are by learning how to change our communication style.

Challenging Communication Situation:

"Where is my mom?"

Avoid Doing This:

- "Your mom passed away a long time ago."
- "Let's do the math. If you are 86 then that would make grandma 116!"
- Visiting the gravesite.

Try This Instead:

- "Where do you think your mom is right now?"
- "Isn't this usually when she is at work?"
- "What would you like to tell her?"
- "I've been thinking about Grandma a lot too."

Challenging Communication Situation:

"I want to go home."

Avoid Doing This:

- "You are in your home."
- "You have lived with me here for several years."
- "Remember, Mom, we sold your home 5 years ago."
- "Well, you can't live in your home anymore. Your doctor says you aren't safe to live alone."

Try This Instead:

- Recall a common memory or story:
 - "I remember that time you painted the living room...."
 - I loved our swingset out back. Tell me what you love about your home."
 - "We signed a month to month lease so we are going to try this out for now."

*often times home is a feeling and may not be the home your loved one recently moved from

Challenging Communication Situation Examples

Challenging Communication Situation:
"I need to get my car! Where are my keys?"

Avoid Doing This:

- "You aren't allowed to drive anymore"
- "You aren't safe to drive, remember?"

Try This Instead:

- Needed an oil change and is in the shop
- Your grandson needed to borrow it
- Someone in the family's car broke down and they needed to borrow it
 - Helping vs stripping things away
 - Providing purpose!
- Have a "letter" from the doctor from the online portal that you print or create on your own

Challenging Communication Situation:
"I need to get to work." or "I need to get on the bus."

Avoid Doing This:

- "You haven't worked in years."
- "You are retired."
- "Calm down. You do not need to be anywhere."
- "There is no bus!"

Try This Instead:

- "You don't have to go in today."
- "It's not time to go in to work yet. Let's enjoy some coffee for a bit."
- "The bus called and it is running late today. Let's have some lunch while we wait."

Challenging Communication Situation:
Care Companion: "Would you like to go to ___ activity?" Response: "No!"

Avoid Doing This:

- Giving up after one try
- Asking a yes/no question if the typical pattern you see is engagement once in a certain activity of interest

Try This Instead:

- "Lets go for a walk." and have that walk end in the activities room to promote engagement and out of room activity. If wanting to leave once there, respect wishes.

Challenging Communication Situation Examples

Challenging Communication Situation:
"Someone is stealing from my apartment."

Avoid Doing This:

- "Nobody is stealing anything from you."
- "It's all in your head."
- "You are just imagining it!"

Try This Instead:

- "Oh my goodness that is terrible. I will talk to the executive director of the building right away."
- "Let's look around to see how this could have happened."
- "Oh my goodness! I cannot believe that! I would be so frustrated!"

Challenging Communication Situation:
"People are looking in my windows at night!"

Avoid Doing This:

- "Stay calm!"
- "There is nobody there! You are just imagining it! It is all in your head."
- "I looked at the security cameras and I do not see anyone there. Your brain is doing this because of your dementia."

Try This Instead:

- Analyze the environment:
 - Remove reflective photos - glass out of frames or mirrors out of the room
 - Remove items that create confusing shadows -
 - stationary bike, armchair with piled laundry, etc.
 - Place a flashlight on the nightstand or motion sensed night lights in the room
- Make a "phone call" to the police station and have your loved one leave a voicemail of their concerns

Challenging Communication Situation:
"Do you see that train going around the ceiling? It must be picking me up soon."

Avoid Doing This:

- "There is no train there."
- "You are just seeing things. There is nothing to worry about."

Try This Instead:

- "Oh, wow! Now that's something I've never seen before!"
- "Where do you think it is going?"
- "I'll go tell the nurse to let them know."

*If this is new, please speak to your healthcare provider to rule out a Urinary Tract Infection or other medical concern

Challenging Communication Situation Examples

Challenging Communication Situation:

"I don't want to go to daycare. I don't need a babysitter!"

Avoid Doing This:

- To start, do not call it an adult daycare.
- "You can't stay here all day by yourself."
- "You aren't safe to be alone."
- Pointing out all of the things you tried to put in place that may not have been successful
 - "You aren't eating the meals I put in the fridge for you and you aren't doing any of the puzzle books I got for you that you said you would do so I need to take you there so that I make sure you aren't just sitting in your chair all day."

Try This Instead:

- "We found a new place in town that has all kinds of activities and serves great meals. Let's go check it out together!"
- "We found a place that is searching for volunteers and we thought you would be a great help!"

Challenging Communication Situation:

"I don't need to take a shower."

"I don't need to change my clothes."

Avoid Doing This:

- "You haven't showered in weeks!"
- "You had on the same thing yesterday."
- "You told me that you showered but I don't see any dirty towels or laundry."

Try This Instead:

- "Let's go into the bathroom."
- "I bought you some new clothes. Let's try them on to see if they fit."
- "You are going out to dinner later. Let's get you all spiffy!"

Challenging Communication Situation Examples

Challenging Communication Situation:

"Are you thirsty?"

"Would you like something to eat?"

- Usually met with, "NO!"

Avoid Doing This:

- "You haven't eaten anything today."
- "You told me you would drink your water and you haven't had any."
- "You are going to get another UTI if you don't drink anything."

Try This Instead:

- "Let's go into the kitchen."
- "Let's take a drink."
- "Let's take a bite."
- "I am trying a new recipe. Let me know what it needs."

Additional Tips:

- Meal plated and ready in the kitchen
- Cup filled
- Contrasting surface
- Hand utensil with 1st bite on it
- Eat together - provide environmental cues

Challenging Communication Situation:

Fixation & Perseveration About Money

Avoid Doing This:

- "Your family is taking care of everything for you."
- "Nothing is wrong with your money. You don't need to worry about it."

Try This Instead:

Helpful Tips:

- Set up online automatic bill pay to decrease anxiety
- Sort through junk mail and discard to eliminate clutter/fraud
- Enter your loved one's reality - leave a "voicemail" with the bank
- Pre-paid debit card in wallet versus credit card

PUT ON YOUR DETECTIVE HAT

Dementia Care Partner: An Agitation & Comfort Checklist



Often persons with dementia have a difficult time expressing what might be bothering them. Some signs of agitation can appear as pacing, aggression, wringing hands, or restlessness. There is often a trigger to what is causing the agitation. This checklist can be a helpful tool to run through possible agitation triggers.

- **Thirsty or hungry?**
- **Tired?**
- **Need to go to the bathroom?**
- **Shirt tag irritating?**
- **Shirt, pants, undergarments, socks, and shoes all on properly? Are these items too tight or twisted?**
- **Is environmental noise too loud?**
- **Glasses comfortably on and clean?**
- **Dentures comfortably in?**
- **Hearing aids in/on and batteries working?**
- **Comfort item present?**
- **Too hot?**
- **Too cold?**
- **Lighting ok?**
- **Urinary Tract Infection (UTI)?**



Resources & Helpful Links

This PDF includes clickable links. Click the button below for helpful resources that can be found on The Memory Compass website or visit www.thememorycompass.com to learn more today!

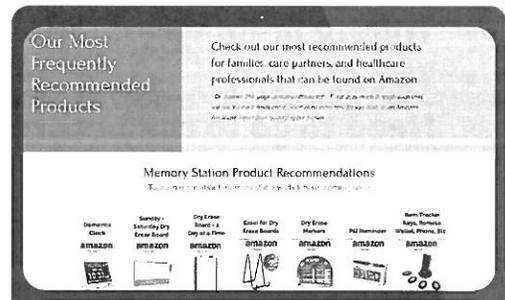
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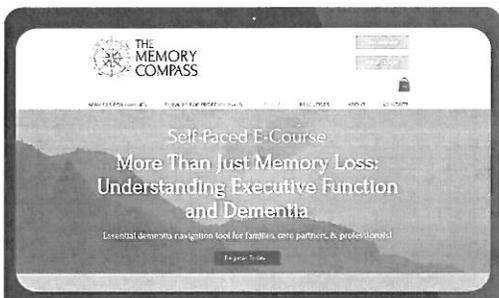
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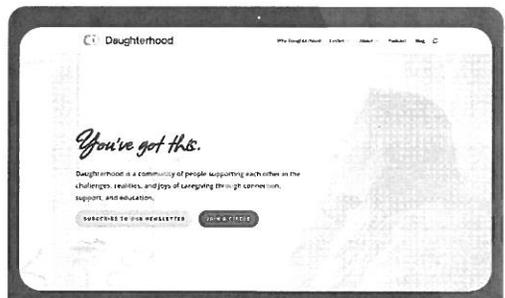
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