

FAMILY &
CAREGIVER
RESOURCE

DEMENTIA RESOURCES

FOR FAMILIES & CAREGIVERS



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INTRODUCTION

This document addresses topics brought up by caregivers as they navigate the dementia journey. Ongoing discussions about these topics can improve the quality of care and reduce caregiver stress. Staying informed, seeking support, and planning ahead when needed ensures a safer and more compassionate caregiving experience. If you have questions on other areas such as sundowning, non-pharmacological approaches, and support groups, please ask your provider.

Topics Addressed in this Document

- Understanding Dementia
- Understanding Compassion and Empathy
- Communication
- Understanding Behaviors
- Mindfulness/Caregiver Well Being
- Dementia Caregiver Tips
- Caregiver Resources

WHAT IS DEMENTIA?

- Dementia is a group of symptoms that can be caused by a number of disorders that affect the brain. People with dementia experience progressive decline in cognitive function including communication abilities and increasing activity limitation. In addition, there are frequent symptoms such as agitation, depression, and psychosis which may occur at any stage of the dementia journey.
- While memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia. Doctors diagnose dementia if two or more brain functions - such as memory, language skills, perception, or cognitive skills including reasoning and judgment - are significantly impaired.

WHAT ARE COMPASSION AND EMPATHY?

- Compassion is an essential component of high-quality care, especially for individuals with dementia. With compassion comes connection, care, and respect. Being able to understand and recognize the situation which the individual with dementia is in and demonstrating empathy by being able to put oneself in the person's place and being able to communicate an understanding of their struggle. The compassionate and empathetic mind acts and responds with warmth and understanding.
- Respect is recognizing the person with dementia's humanity and maintaining their dignity. It involves actively listening and demonstrating a non-judgmental approach. Individuals with dementia still have a voice - allow them to be heard.

COMMUNICATION

Verbal Communication Techniques

- Addressing the person by name and using greetings helps establish a connection and foster respect.
- Providing short, clear instructions and breaking down tasks into manageable steps can support comprehension and reduce anxiety and resistance. For example, 'We're going to brush your teeth now.'
- Positive reinforcement, such as giving praise and positive feedback when the person with dementia follows directions, encourages their participation, while repeated positive messages can provide reassurance and reduce stress.
- Indirect repair, where a listener repeats or rephrases a statement to maintain conversational flow without correcting the person, is effective in keeping communication smooth and nonconfrontational.

Avoid Elderspeak

- Avoid childish phrases ('Do you need a blankie?'), endearment names ('sweetheart, honey, baby'), and belittling language ('Shall we go potty?'), which are often counterproductive and associated with increased resistance to care.
- Overloading people with dementia with excessive information or instructions can be overwhelming and hinder communication. Asking specific recall questions can also cause distress (Don't you remember?).
- Using jargon, acronyms, or complex language can create barriers, given the language comprehension difficulties in dementia.

Nonverbal Communication Techniques

- Nonverbal communication is vital in interacting with people with dementia. Physical contact (with permission), such as a pat on the shoulder or a hug, offers reassurance and establishes rapport for effective communication.
- Paying attention to voice features - such as tone and speech rate - ensures communication is attuned to people's emotional and cognitive needs.
- Gestures like pointing or demonstrating actions help direct a person's focus to specific tasks or objects, while tactile prompts, such as handing an object or guided touch, capture attention and aid understanding.
- Creating an atmosphere conducive to communication is also achieved through eye contact and appropriate facial expressions.

Use of External Aids

- Visual memory aids and memory books, with pictures and words, can help people with dementia recall and express valuable information about themselves and engage in meaningful interactions.
- Images can also support in understanding questions about their social and leisure-based preferences.

WHAT IS A BEHAVIOR?

- Behavior is the way in which one acts or conducts oneself, especially toward others. It is a form of communication. Behavior is often the expression or communication by the person with dementia in response to a need that is not being met. 'Walk a mile in their shoes.' When we imagine ourselves in someone else's shoes and try to view the world through their eyes, we are better able to interpret their behaviors. It is important to not assume the behavior is happening only because they have dementia. Ask yourself, 'Why is this happening?'
- Behaviors often reflect an attempt by the person with dementia to maintain:
 - A sense of control, dignity, and wellbeing
 - Ease discomfort where normal forms of verbal communication may no longer be available to them or an unmet need.
- As the type of dementia progresses, senses become heightened. For example:
 - Are their hearing aids in correctly and batteries are working?
 - Are their eyeglasses clean and smudge-free?
 - Are they using new equipment such as a cane, walker, wheelchair?
- It is important to 'enter their world and reality.' They are the ones with the type of dementia - have compassion and empathy - understand how they are feeling.

Challenges - What to look for and What do to

Agitation and Anxiety

What to look for:

- Most often, agitation is triggered when the person experiences / senses "control" being taken away.

What to do:

- Reduce noise, clutter, or the number of people in the room.
- Maintain structure by keeping the same routines.
- Wayfinding - keep objects / furniture in the same places.
- Speak in a reassuring voice.
- Redirect with a snack or an activity.

Wandering

What to look for:

- Walking, aimlessly, for a variety of reasons, such as boredom, medication side effects, or looking for something or someone.
- Becoming restless, pacing, or making repetitive movements.
- May be trying to fulfill a physical need - thirst, hunger, a need to use the bathroom, or exercise.

What to do:

- Offer snack(s) to replenish caloric intake.
- Create a pathway of purpose.
- Provide opportunities for the person to engage in structured, meaningful activities throughout the day.
- Identify the time of day the person is most likely to wander (for people who experience sundowning, this may start in the early evening). Plan things to do during this time - activities and exercise may help reduce anxiety, agitation, and restlessness.
- Ensure all basic needs are met, including nutrition, hydration, and going to the bathroom.

Hallucinations and Delusions

What to look for:

- Hallucinations (seeing or hearing things that others do not).
- Delusions (false beliefs, such as someone is trying to hurt another) may occur as dementia progresses.

What to do:

- Keep rooms well-lit to decrease shadows.
- Avoid arguing or trying to convince the person his / her perceptions are wrong.
- Offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard.

CAREGIVER WELL BEING - MINDFULNESS MATTERS

Caregiving is a critical part of a strong society. Caregivers provide support to those who are elderly, young, or in need of direct aid, and they also contribute to the fabric of the overall community. Caring and caregiving are critical to individual and collective wellbeing.

What is Mindfulness?

Mindfulness is a powerful tool for managing stress and enhancing focus, offering many benefits for both mental and physical health. By cultivating mindfulness, caregivers can improve their ability to concentrate, reduce anxiety, and enhance overall well-being.

Mindfulness is:

- A state of active, open attention to the present.
- Nonjudgmental awareness of one's own thoughts, feelings, and senses.
- Helping caregivers be more focused and productive.
- Building mental strength and emotional resilience.

7 TIPS TO CARING FOR A LOVED ONE WITH DEMENTIA

Here are some key tips to help care for individuals with dementia:

1. Enter their world. People with dementia make sense to themselves. Refrain from arguing or correcting the person if they are confused or delusional. Go along with it, provide reassurance. For example, if Mom says, "I'm waiting for Dad to pick me up" (and Dad is deceased), say, "Tell me again how you and Dad first met."

2. Validate their feelings. Reassure your loved one that they are loved. People with dementia may get frustrated and lash out at the ones they are closest to. For example, if Dad fights you when you are helping him get dressed, stay calm. Say, "I can see you are uncomfortable in that sweater. Let me get you a different one."

3. Redirect their focus. Shift your loved one's attention away from something stressful and toward something pleasant. For example, when Mom gets anxious, encourage her to cuddle the family pet, show her a funny YouTube video, or photographs of the grandkids.

4. Apologize and take the blame. Even when you are not at fault, an apology defuses a tense situation. Keep it simple, "I'm sorry I misunderstood."

5. Change the environment. People with dementia can become agitated by or fixated on something in their surroundings. They might get upset by newspapers on the kitchen counter or want to use tools they see in the garage. Move disturbing or potentially dangerous items out of the way. Create a calm, well-ordered place for your loved one to go to, such as a garden area or a quiet room.

6. Give simple choices. Your loved one may feel as if they no longer have any say over their life. Letting them make small decisions helps them feel in control. Ask "Would you like eggs or cereal for breakfast?" instead of setting down a bowl of corn flakes. Providing choices also engages the person in decision making and encourages participation in their care.

7. Involve them in meaningful activities. Research shows that participating in physical, mental, and social activities reduces stress and anxiety for people with dementia. Try art, music, reading with them, or going for a walk if able. If a group activity or outing is too much, invite a good friend over for coffee or lunch.

CAREGIVER RESOURCES

AARP - www.aarp.org - This website provides information about Caregiving Tools that may be especially helpful.

Aging in Place - www.aginginplace.org - Look here for links to supportive and caregiver services, nutrition and health promotion programs, and elder justice and adult protective services.

Alzheimer's Association - www.alz.org - This website provides information about Alzheimer's disease and other dementias, life with Alzheimer's, and services in the We Can Help section. <https://www.alz.org/alzheimers-dementia/what-is-dementia>

American Geriatrics Society - www.americangeriatrics.org - Click on Public Education to check out the information available at the Health in Aging Foundation.

Caregiving Topics - <https://www.agingcare.com/topics>

Dementia, Behavioral & Mental Health Resources - <https://www.wowt.com/news/now-what/>

Institute for Healthcare Improvement (IHI) Conversation Starter Guide - <https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf>

National Hospice and Palliative Care Organization - <http://www.nhpco.org> - Under the Resources tab is an abundance of information helpful to families about hospice and palliative care, access, and caregiving.

National Institute on Aging - <https://www.nia.nih.gov/alzheimers> - This website provides a wealth of information about topics of interest to families.

National Institutes of Health - <http://www.nih.gov/health-information> - The Health Information section offers particulars on several topics.

Now What? - <https://www.wowt.com/news/now-what/> - Educational television programs about health care topics including dementia, Parkinson's disease, and mental / behavioral health.

Ten Tips for Family Caregivers: Balancing Caregiving and Self-Care - <https://caregiveraction.org/resources/10-tips-family-caregivers> - These tips you can use on daily basis to make your tasks easier and make sure you are not neglecting your own needs.