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## **Understanding Dementia and the Four Ds of Dementia Care**

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#### About Tami

Tami is a dementia consultant, educator, speaker, and author of [Essential Strategies for the Dementia Caregiver: Learning to PACE Yourself](#). She helps families navigate this journey from beginning to end. Tami also **has** a private practice and provides dementia guidance, counseling, care strategies, emotional support for family and professional caregivers, and provides counseling services for people early diagnosed with dementia (listening, reassurance, providing patients with a voice). Last but not least, Tami facilitates twice-monthly caregiving support groups (2nd and 4th Wednesday in Feb, and will switch 2nd and 4th Tuesday starting in March).

#### What is Dementia?

Dementia causes brain damage, which in turn causes functional impairments. People with dementia will gradually lose simple self-care functions. Common symptoms are: memory loss, irrational thinking, increased confusion, and distorted perception. How these manifest is that people with dementia do not have control of the things they say or do. They lose the ability to censor or filter what they are thinking and they lose the ability to process information logically and rationally. This can be a humiliating experience to both the patients and caregivers, as patients may say and do things that are hurtful, inappropriate, or embarrassing. People with dementia do not say and do things intentionally to be offensive or hurtful. As dementia progresses, patients often can't do what is asked of them because they truly lack the capacity to follow instructions.

Progression of the dementia varies from person to person. Each person can be on a different trajectory. A typical trajectory can look like the person levels out for a while, then takes a step down, then level out for a while before another step down, and the length of each level and the magnitude of each step down can vary.

One important thing to note is that all behaviors from a person with dementia are a form of communication. It's important to try to figure out what the patient is trying to communicate. These are some common situations:

- When a loved one appears to be angry, there could be a trigger that caused them to re-live an unpleasant situation or memory that happened

in their past

- When a loved one appears to be lying, they aren't lying - they confabulate - they say things that aren't true or inaccurate because of the damage done to their brain and they aren't aware that the information is inaccurate. They are just repeating what their brain is telling them (e.g. things missing must be stolen by caregivers).
- When a loved one appears to be lazy, they are being lazy, it's often apathy setting in. As dementia progresses, the patient loses the ability to motivate themselves to do things. They will need encouragement and assistance "engaging" in activities.

Tami portrays the person with dementia to give us a better understanding of their behaviors

1. I'll repeat things over and over again because of my short term memory loss. I'm not even aware that I'm repeating things over and over!
  - As my caregiver, please listen to what I'm telling you - there are often themes - I'm telling you things that might be important, memorable, afraid of, frustrated with, or concerned about. Please listen to understand. What're the feelings behind the words? What do I want you to know?
2. I will forget about things that I just said.
  - This is because my brain is impaired due to damage to my brain cells.
3. I may accuse you of stealing!!
  - Due to my short term memory loss, I don't have any recollection of where I moved that "lost" item. And since I have no memory of placing it anywhere else, if I can't find it where I think it should be, my brain thinks someone must have stolen or hid it!
4. I may become argumentative!
  - I believe what my brain is telling me. If you disagree/correct/argue with me, I am compelled to defend my thinking, without knowing that my thinking is actually impaired, irrational, or distorted.
  - Please do not be dismissive. I need to feel heard and understood. I need reassurance that things are okay.
5. I may appear to be uncooperative!
  - This is because I may not understand what's being asked of me or I simply don't know how to do it. And, I'm not able to process a lot of information at one time.
  - I lose the ability to do things in sequence. Bathing for example takes 57 steps so I certainly can't do that by myself if I've lost my sequential memory!

- You need to slow down and show me how to do things one step at a time. For example, rather than saying "let's hurry up so you won't be late for your appointment", you can start with "let's put on our shoes and then let's stand up".

6. I may say things that are offensive!

- Self awareness is stored in the frontotemporal part of the brain. Dementia causes damage in those regions, so I don't have the capacity to be self-aware.
- Due to loss of sensory and filtering capacity, I may blurt out things that are offensive but it's not intentional. Also, please be aware that I become hypersensitive to everything - body language, facial expression, tone of voice etc.
- Know that I don't intentionally say anything offensive to hurt you.
- Try to understand and connect with me at my current level. Don't keep pointing out my problems/limitations. Know that my brain is impaired!

7. I hate it when I am rushed!

- I may have a ritual or routine that makes me feel safe, secure, and in control. If you try rushing me and I skip my ritual/routine, it may make me feel like I'm losing control and I will react to that. Please build in extra time for any appointment.

## The 4Ds of Dementia

### **Detach**

- Try not to take what your loved one says and does personally. I know this is easier said than done.
- Listen to learn. Listen to understand
- Validate what your loved one is telling you. You don't have to agree or disagree. Paraphrase or repeat back what you heard followed by a reassuring and comforting response

### **Diffuse**

- Replace saying "you" with "we and us." For example, instead of saying it's time for you to take your medication - say it's time for "us" to take our medication.
- Reframe what you want me to do. Invite me. Demonstrate how to do it
- Remember safety always comes first and compliments go a long way

## Document

- There's often patterns/triggers that cause certain behaviors, e.g. color of clothing can be a trigger
- Patients can be reliving a past traumatic experience from that trigger and if known can possibly circumvent
- Know what makes me happy and what motivates me.

## Distract

People with dementia need to feel a sense of purpose and value. Engage them in activities that they enjoy and can be done at their level of ability,

Ask your loved one to do things but simplify the tasks. Find the level of ability that they can still do. People with dementia don't want to feel useless. When they don't feel a sense of purpose or value they'll often say "I don't want to be a burden" or they feel defective.

Both food and music are wonderful distractions!! For music, caregivers should pay attention to the era of music that the patient under care enjoys. And, food can be very comforting.

## Message to the Caregivers

The Dementia journey is far harder on the caregivers, who are losing connection to their loved ones and they have to find new ways to connect with them.

- Challenge is entering into their loved one's altered world.
- Feeling frustrated and helpless when a loved one refuses their help.
- Guilt from moving a loved one into a caring community.

Fundamentally, dementia alters the relationship and connection between the family caregiver and their loved one. As a caregiver, do not judge yourself. **You are doing the best you can. Give yourself credit for the love, care and support you provide everyday.** Mistakes are an opportunity to learn from! Try not to judge and criticize yourself!

## Q&A

Q: When to bring in a caregiver into the home and how to frame the conversation?

A: Avoid saying "you need help". Come up with a story as to who the caregiver is and present it in a way that appeals to your loved one (e.g. a student teacher coming to learn from a great teacher, an admin assistant etc.). Think about how

you approach/present the caregiver to your loved one. Avoid presenting the person as a "helper".

You also need to come up with priorities for the care helper to do at home, e.g. cognitive, physical, or social stimulation. Try to offer something that is appealing to your loved one

Q: What are some strategies and tips to move someone with dementia from home to care facility?

A: Transitions can be especially difficult for people living with dementia as well as for the family caregiver. Make the new environment as similar to the current settings as possible. Friends in the new environment can help, e.g. throw a welcoming party. Avoid using the word "move". Say *people can't wait to see us* (don't say "you"). *People love you!!* Tap into what appeals to your loved one. Don't give the impression that it's permanent, e.g. say "*let's give it a try*", "*we will see how it goes*", etc. Timing (when and what to tell your loved one) is important depending on how advanced the dementia is - sometimes too much advance notice can cause anxiety.

Q: What are the roles of the adult children and their spouses?

A: The key is to be willing to let go of the relationship pre-dementia. Try to re-learn and reconnect with the "new" person. Be open to accepting a loved one with an impaired brain. There will be opportunities to listen and to learn something new (and these can be beautiful moments). Try to find these beautiful moments in a non-verbal setting, e.g. holding hands, kissing on the cheek, rubbing back, hugging, listening to music, laughing together, etc.

Q: How to deal with hurt?

A: Caregivers will feel judged or hurt when their loved one says negative things about them. "My mom treats me like a teenager and it really infuriates me!" Remember that your loved one doesn't have control. One strategy is Quit Taking It Personally (QTIP).

Q: When to declare incapacitated?

A: It's a legal question. Get a medical diagnosis first if possible.

Q: Is dementia genetic?

A: Many people are concerned that dementia is inherited. Currently, this isn't definitive. The number one risk factor is age. And, there are many other risk factors (e.g. other medical conditions, falls, lifestyle habits, family history with dementia, etc.) can increase the risk, but this doesn't mean causation.