

Caring for a Person with Dementia...

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Overview

Caring for a person with dementia requires:

- ❖ That we understand the disease process
- ❖ A change in perspective
- ❖ Learning a new way to communicate
- ❖ Understanding and accepting our emotions
- ❖ Flexibility
- ❖ Being present in the moment

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Caring for a Person with Dementia

Requires that we know and understand the disease process.

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Dementia versus Alzheimer's Disease

Dementia

A word for a group of symptoms caused by disorders that affect the brain.

Cognitive and or Behavioral Decline:

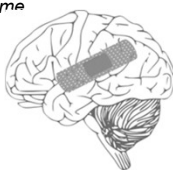
- Memory
- Temperament
- Orientation
- Judgment
- Language
- Concentration
- Thinking
- Visual Perception

A Variety of Causes:
 Stroke; Parkinson's; Alzheimer's; Vascular Dementia; Lewy Body (**irreversible**)
 Vitamin deficiencies (B12), thyroid conditions, diabetes, heart disease; Depression (**reversible**)

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Alzheimer's Disease

- ❖ Most common form of dementia
- ❖ Irreversible
- ❖ Progressive
- ❖ Regressive
 - *Memories and abilities decline over time*
- ❖ Hallmark-short term memory loss
- ❖ "Broken Brain"
- ❖ No cure to date
- ❖ Effects everyone differently



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Trajectory

	Early	Middle	Late	Final
Independence	Memory Thinking Disorientation	2-10 years Abilities 8 - 5 years of age	Resistiveness Incontinence Eating Difficulties Motor Impairment	6 months Abilities 15 mos to infant.
	1-2 years Abilities 12 years and older in age	Language problems Putting words into action	1-3 years Abilities 5-2 years of age	Bedfast Mute Trouble swallowing Infections
		Confusion Agitation Insomnia		Death

Time

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Caregiving Challenges

* Safety concerns

- * Driving
- * Preparing meals (fire, spoiled food)
- * Wandering-getting lost
- * Medication management

* Changes in Mood

- * Anxious / fretful / fidgeting
- * Agitated / combative
- * Sleep disturbances

* Resistance to Care

- * Bathing / brushing teeth
- * Dressing
- * Eating
- * Toileting

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Caring for a Person with Dementia

Requires a change in perspective

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A Different Perspective



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A Personal Perspective

Image : William Utermohlen, Self Portrait (green), oil on canvas. Google images, 2012
<http://www.artlyst.com/events/art-alzheimers-gv-art>



"I am a verb – I be, I do. Exactly what I be and how I do depends on my disease..."~Richard Taylor
Alzheimer's from the Inside Out, 2006

"I make an effort to put everything where I think I know it is and then I go back and it's not there. I probably moved it. It's frustrating..." – Bea
 L. Snyder, *Speaking Our Minds*, 2009

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Caring for a Person with Dementia Requires an Understanding of Behaviors

"Human behavior flows from three main sources: desire, emotion, and knowledge."

~ Plato



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Stages and Behaviors

"One day I was driving into town... I was supposed to make a left turn but instead I went straight ahead into oncoming traffic" - Bea

Early stages – still has awareness of self despite memory impairment; can function with minimal assistance.

- ❖ May misplace or forget where put keys, purse, other objects
- ❖ Resist giving up the car keys or offers of help
- ❖ **Can lash out verbally, be argumentative due to loss of control, fear**
- ❖ Some difficulty writing and using objects
- ❖ Word finding problems, may repeat themselves and have trouble keeping pace during a conversation
- ❖ Lost or confused in unfamiliar places
- ❖ Routine chores may be more difficult

❖ **May needs reminders and or assistance with finances, housekeeping chores, oversight of medications. Safety considerations**

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Stages and Behaviors

Middle Stages – diminished ability to care for self and ability to interpret surroundings. Increased memory loss

- ❖ **May see more behaviors** – *wandering, repetitive questioning*
- ❖ **May become suspicious and accusing**
- ❖ **Combative when pushed beyond limits**
- ❖ **May refuse a request**
- ❖ Difficulty organizing thoughts, actions or thinking logically
- ❖ Difficulty with personal care

❖ **Needs help with personal care, bathing, dressing, toileting; needs structure and routine; may need 24-hour supervision**

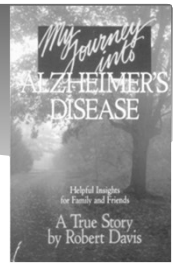
"...he fumbles with his jockey pants...he puts them on backwards, squirming, uncomfortable, before pulling them off...finally he locates the label...and steps in correctly." - A. Davidson, *A Curious Kind of Widow*, 2006

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"I am still the same person, but I just can't do my work anymore. I know that one of these days I will not be in here anymore, but for now, I am still home in here and I need your friendship and acceptance."

~ Robert Davis

[My Journey into Alzheimer's Disease](#)



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Stages and Behaviors

Later Stages communication, memory and ability to care for self severely diminished.

- ❖ Lacks words to communicate needs
- ❖ May not recognize family or friends
- ❖ Mixes up past and present
- ❖ **May call out for help, yell, or scream**
- ❖ **Easily upset and agitated**
- ❖ **Resistive to bathing, dressing and other personal care**
- ❖ Incontinent, difficulty eating

❖ **Needs 24-hour care and supervision**

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Stages and Behaviors

Final Stage- Has no clear link to past or present, totally dependent on others.

- ❖ Mute or incoherent speech
- ❖ Weight loss and poor oral intake
- ❖ Does not appear to recognize surrounds (blank stare)
- ❖ Limited movement; swallowing difficulties; at risk for aspiration pneumonia
- ❖ Completely passive, bed bound

❖ **Needs total assistance and support; Connect to person via touch / sound / taste. Hospice should be considered.**

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What Are Behaviors?

- ❖ Actions meant to communicate.
- ❖ Responses to an unmet need.
- ❖ Messages with personal meaning.
- ❖ Reaction to a perceived threat.
- ❖ Normal part of our lives.



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What Causes Behaviors?

- ❖ Stress of coping with cognitive and functional changes
- ❖ Stress of coping with changes in "routine"
- ❖ Stress of coping with changes in the environment
- ❖ Stress of coping with demands of other
- ❖ Stress of not understanding what is happening to or around them

PEOPLE WITH DEMENTIA LOSE THE ABILITY TO COPE WITH STRESS

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TRIGGERS

- * **Physical**
 - * Pain, Hungry, thirst
 - * Toileting needs
 - * Infections
 - * Medications
 - * Metabolic changes
- * **Emotional**
 - * Lost
 - * Lonely
 - * Worried
 - * Confused
 - * Worried / Upset
- * **Environmental**
 - * Clutter
 - * Temperature
 - * Objects/ Visual cue
 - * Over/under stimulated
- * **Approach**
 - * Tone of voice
 - * Posture
 - * Choice of words
 - * Addressing task not person

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Things to consider when a behavior occurs

- ❖ Did the person respond differently to this situation than she/he has in the past?
- ❖ What usually calms the person?
- ❖ Use redirection or attempt to refocus
- ❖ Be aware of changes in the environment and the person's routine
- ❖ Be careful not to place too many demands on the person
- ❖ Give the person choices
- ❖ How did they cope with stress in the past? (physical, emotional, retreat)

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How to Help Reduce Behaviors *Can't always eliminate*

- * **Accept that you can't change them**
 - * Walk in their "shoes"
 - * Identify the **TRIGGERS**
 - * Be patient and remain calm
 - * Establish a routine
 - * Slow down, don't rush the person
 - * Maintain eye contact
 - * Inform them of what you want to do
 - * Support remaining abilities
-
- * **Ask: What Does this Person Need from Me?**
 - * To be heard?
 - * To be loved?
 - * To be understood?
 - * To be helped?
 - * To be left alone?

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Support Remaining Abilities

- ❖ Take a friendly and patient approach
- ❖ Offer compliments and praise
- ❖ Allow person to have as much control as possible
- ❖ Remove distractions from the environment
- ❖ Break tasks into simple steps
- ❖ Speak in short simple sentences
- ❖ Follow person's routine
- ❖ Assess for pain and discomfort - Medicate prior to task

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Validate the Person's Perspective and Feelings

- * As disease progresses people with dementia may relive past life experiences.
 - * They use remaining memories to make sense of the world.
- Respond to the emotional feeling** – "I can't find my purse."
"I would be upset too..."
- Be in the moment** – "I need to go home."
"Your children are safe at school".
- Help solve the problem** - "I have to go to the doctor today."
"The doctor cancelled your appointment".

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Caring for a Person with Dementia

Requires learning a new way to communicate.

"The worst affliction is not being able to speak... I am able to bring thoughts in but can't get them out"
– Bill

L. Snyder, *Speaking Our Minds*, 2009

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Consequences of Poor Communication

Person with AD

- ❖ Frustrated
- ❖ Agitated, upset
- ❖ Withdrawn
- ❖ Needs go unmet
- ❖ Diminished quality of Life
- ❖ Loss of connection to self and others

Caregiver

- ❖ Frustrated
- ❖ Upset
- ❖ Unable to meet needs of person with AD
- ❖ Loss of relationship

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Communication Changes Over Time

- ❖ **Early stage:** Difficulty finding the right word, may repeat themselves and have trouble keeping pace during a conversation.
- ❖ **Middle stage:** Increased difficulty with speaking correctly & understanding what others are saying.
- ❖ **Late stage:** Vocabulary reduced to a few words or phrases; increased need for nonverbal cues
- ❖ **Final stage:** Mute or occasional word/phrase

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Enhancing Communication

1. **Do listen carefully.**
They often eventually make sense.
2. **Do help a person fill in the blanks.**
It can keep the conversation moving.
3. **Do give compliments.**
Compliments take seconds, don't cost any money and lift the person's spirits

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Enhancing Communication

4. **Do ask opinions.**
It shows that he/she is valued.
5. **Do take the blame when things are not going well.**
6. **Do keep language simple and concrete.**

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Enhancing Communication

7. **Do watch your body language.**
An upbeat attitude and smile are received positively by people with AD. They are looking for a friendly face!
8. **Do not argue, confront or correct.**
It doesn't work and creates conflict.
9. **Do not give orders or make demands.**
The person will sense your pushy attitude and will resist

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Enhancing Communication

10. **Do not talk down to the person.**
It is not kind and the person will sense a poor attitude.
11. **Do not treat anyone like a child.**
Many people enjoy child-like activities, but begin with an adult relationship.
12. **Do not talk in the person's presence as though not there.**
It is demeaning.
13. **Do not ask complex questions.**
It will cause frustration – for you and them.

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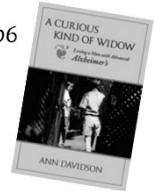
When you have trouble Understanding

- ❖ Focus on a word or phrase that may have meaning and the person's body language.
- ❖ Try to stay calm and be patient
- ❖ Respond to the emotional tone and validate

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"Today, oddly, Julian isn't frustrated,....He just needs me to respond in a kind, chatty way. It no longer matters what I say. He mostly responds to how I speak, the tone of my voice, the mood he senses in me."

A. Davidson, *A Curious Kind of Widow*, 2006



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When Words Fail

- ❖ Use songs, stories or prayers
 - ❖ Use props, cues & gestures
 - ❖ Use touch
- "We sit on the bench, holding hands, my head resting on his shoulder, both of us squinting into the blazing orange disk of the setting sun."*
- A. Davidson, *A Curious Kind of Widow*, 2006

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Caring for someone with Dementia

Requires adapting to changes in roles and responsibilities

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Changes in Roles & Responsibilities


- ❖ Household chores
- ❖ Managing money
- ❖ Handling healthcare
- ❖ Driving a car
- ❖ Personal care
- ❖ Intimacy & sexuality
- ❖ Hiring help
- ❖ Moving to care facility
- ❖ End-of-life decisions

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Caring for someone with Dementia

Requires understanding and accepting our feelings and learning to cope with loss and grief

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“ ...it came to me as a revelation that amidst all the losses, the essence of this man I loved was still very much present. Sometimes my own preoccupation obscured my seeing, but astonishingly there he would be - the wholeness of his spirit shining through – his acuity, his sensitivity, his playfulness and humor all intact. “

- O. Ames Hoblitzel, *The Majesty of Your Loving*, 2008
(*Ten Thousand Joys and Ten Thousand Sorrows*, 2nd Edition)

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Caregiving involves a range of feelings

- ❖ Important to identify our feelings
- ❖ Can be both positive and negative
- ❖ Often contradictory
 - Anger, frustration, resentment
 - Love, hope, happiness
- ❖ Often accompany a loss

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Coping with loss

- ❖ Accept what can't change
- ❖ Redefine the relationship
- ❖ Change thinking or refrain viewpoint
 - “both/and” technique
 - “I'm sad that my wife can no longer communicate with me and glad that we still can be together holding hands”


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With loss, comes grief

- ❖ Grief is a natural response when we lose something that is important to us.
- ❖ Grief comes with strong emotions
- ❖ Each person responds differently
- ❖ Important to allow yourself time to grieve
- ❖ Ongoing process
- ❖ Leads to acceptance and allows us to move forward

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Marvin and Jackie



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Caring for someone with Dementia

Requires flexibility and being present in the moment

“Life isn't about waiting for the storm to pass. The great lesson is to learn to dance in the rain.”
- Anonymous

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Being Flexible Requires

- ❖ Adapting to changes as dementia progresses
- ❖ Redefining the relationship - becoming a "best friend"
- ❖ Focusing on the possibilities

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Creating and Maintaining the Relationship

- ❖ Create a daily routine
- ❖ Use reminiscence
- ❖ Do things you enjoy together but remain flexible
- ❖ Create opportunities for person to be successful
- ❖ Keep person engaged in activities you both enjoy - adapt as needed
- ❖ Provide choice and control

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Living in the Moment

Let it be a dance we do
 May I have this dance with you?
 Through the good times
 and the bad times too
 Let it be a dance.
 Let the sun shine, let it rain.
 Share the laughter, bare the pain
 and round and round we go again
 so let it be a dance.

Author: Ric Masten



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Resources

Alzheimer's Association www.alz.org
 24/7 Helpline 1-800-272-3900

- ❖ V. Bell and D. Troxel, *A Dignified Life: The Best Friends Approach to Alzheimer's Care*, 2002
- ❖ D. Kuhn, *Alzheimer's Early Stages*, 2003
- ❖ J. Koenig Coste, *Learning to Speak Alzheimer's*, 2003
- ❖ A. Davidson, *A Curious Kind of Widow*, 2006
- ❖ O. Ames Hoblitzel, *The Majesty of Your Loving*, 2008
- ❖ J. Brackey, *Creating Moments of Joy*, 2007
- ❖ G. Chapman, D. Barr, E. Shaw, *Keeping Love Alive as Memories Fade: The 5 Love Languages and the Alzheimer's Journey*, 2016

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