

**EMBRACE AGING:
Caregiving in a World of
Dementia & Alzheimer's Disease**
Calvin Community Foundation/AARP IOWA



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**EMBRACE AGING:
Caregiving in a World of
Dementia & Alzheimer's Disease**

- Understanding Alzheimer's Disease
- Guiding Principles for Caregivers & Families
- Behavior Management
- Communication Tips
- Skills For Success
 - Redirecting
 - Plugging them In
- Moments of Joy
- Summary, Questions & Adjournment

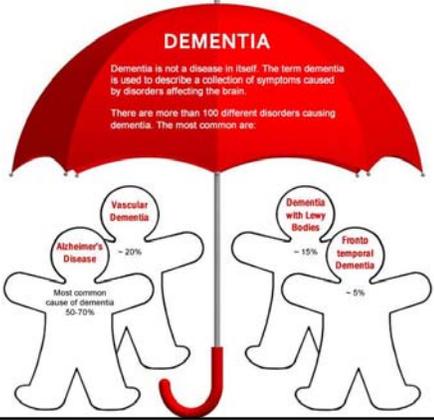
Dementia vs. Alzheimer's



DEMENTIA

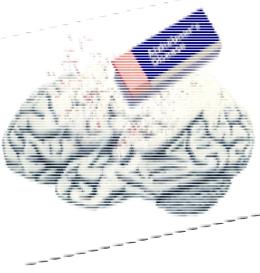
Dementia is not a disease in itself. The term dementia is used to describe a collection of symptoms caused by disorders affecting the brain.

There are more than 100 different disorders causing dementia. The most common are:



Definition of Alzheimer's

- Insidious onset with progressive decline of cognitive function resulting in impairment of social or occupational functioning from a previously higher level



Definition of Alzheimer's (cont'd)

- Impairment of recent memory and at least one of the following cognitive domains:
 - Aphasia: language comprehension & use
 - Apraxia: learned motor sequences
 - Agnosia: ability to recognize objects & use
 - Executive function: planning, organizing, sequencing, and abstracting

Two Categories of Alzheimer's Disease

FAMILIAL

- Rare <5% of cases
- Inherited
- Early onset < 60 yrs old
- Chromosomes 17, 21, 14 & 1 are involved
- NO single gene

SPORADIC

- 95%
- Not inherited
- Late onset > 60 yrs old
- Chromosome 19
- ApoE4

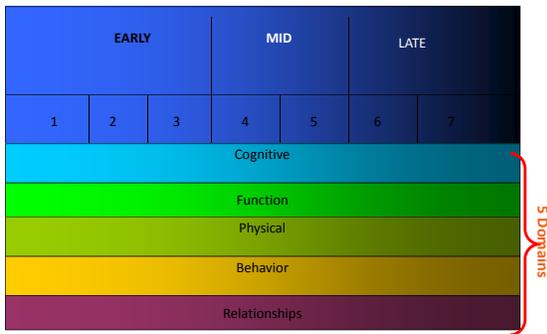
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Alzheimer's 7-5-8

- 7 - Stages of the Disease
- 5 - Domains Affected
- 8 - Cognitive Powers Lost

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7 Stages & 5 Domains



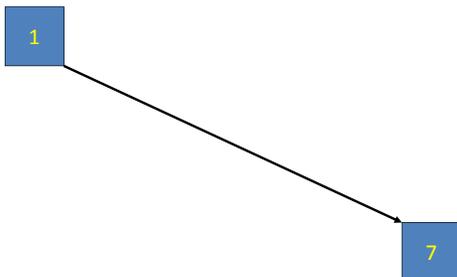
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7 Stages

- Stage 1 – No impairment
- Stage 2 – Very mild cognitive decline
- Stage 3 – Mild cognitive decline
- Stage 4 – Moderate cognitive decline
- Stage 5 – Moderately severe cognitive decline
- Stage 6 – Severe cognitive decline
- Stage 7 – Very severe cognitive decline

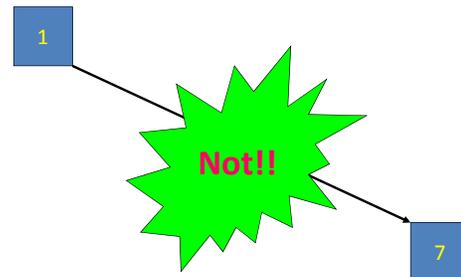
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Progression of Stages: A Straight Line?

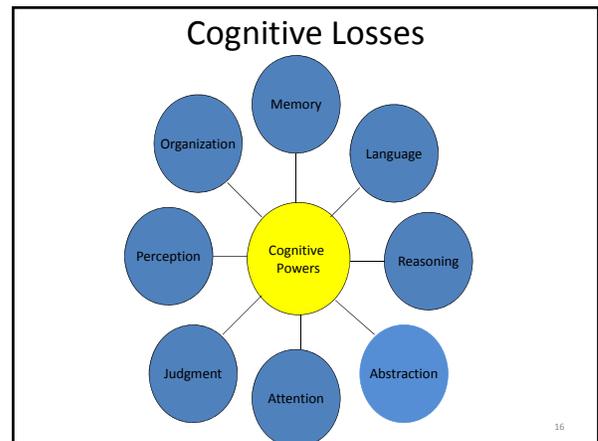
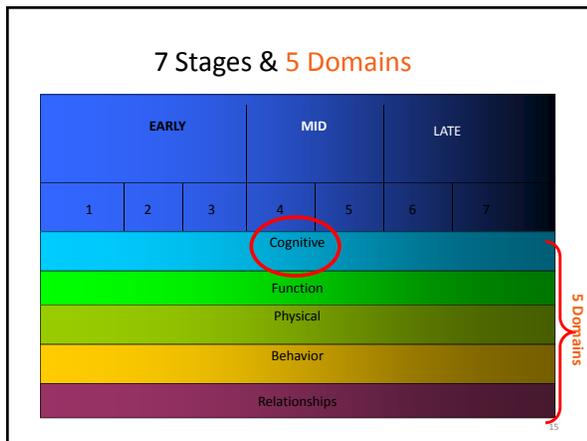
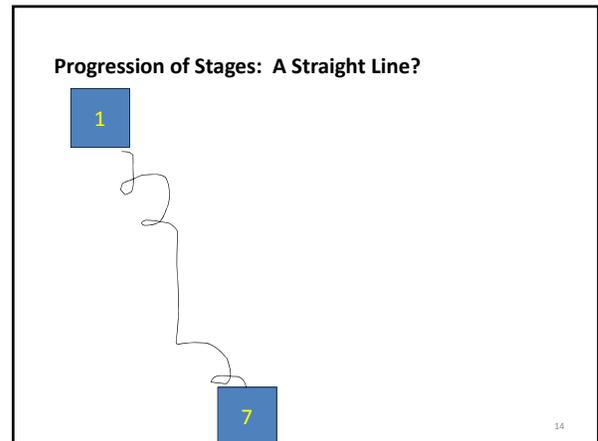
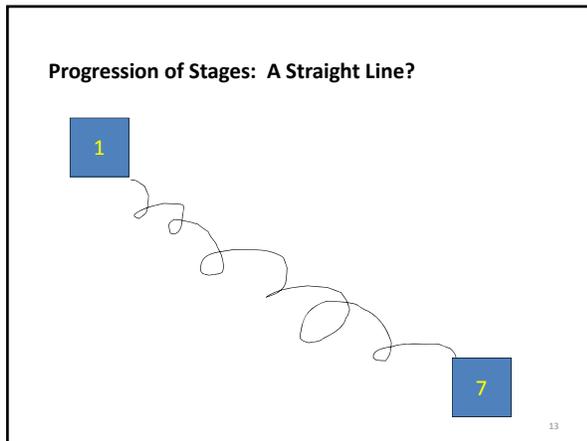


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Progression of Stages: A Straight Line?



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- In Summary:**
- Alzheimer's is a specific type of dementia
 - There are 70 known types of dementia
 - ALZ is a serious disease – mental and physical deterioration – requires very specialized care
 - 4 Guiding Principles which caregivers and families can use in managing the care of loved ones with Alzheimer's
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Guiding Principles for Alzheimer's & Dementia Care

Treat the disease very seriously, but...

- ① Don't allow the disease too much power
- ② Maintain personhood despite the disease
- ③ Recognize the person's rights
- ④ Recognize unique needs of the individual

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Guiding Principle #1: Don't Allow The Disease Too Much Power



-All other principles, tools and tips
support this one!!!!

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Guiding Principle #2: Maintain the Individual's Personhood Despite The Disease

Focus on the Person,
NOT on the Disease

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What Makes Us A Person?

We can

- Think
- Talk
- Reason
- Plan
- Solve problems

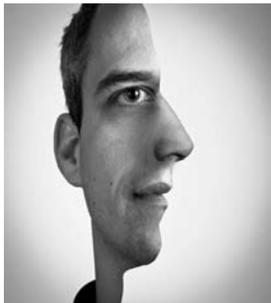


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What Makes Us a UNIQUE Person?

HOW we...

- Think
- Talk
- Reason
- Plan
- Solve problems



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Therefore...

If Alzheimer's disease takes away our capacity to:

- Think
- Talk
- Reason
- Plan
- Solve problems

...does it take away our capacity to be a unique individual?

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Personhood: Despite the Disease,
the Person Is Still There



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Guiding Principle #3: Recognize
The Person's Rights



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Alzheimer's Bill of Rights*

- To be informed of one's diagnosis
- To have appropriate, ongoing medical care
- To be productive in work & play as long as possible
- To be treated like an adult, not a child
- To have expressed feelings taken seriously
- To be free of psychotropic medications if at all possible

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Alzheimer's Bill of Rights*

- To live in a safe, structured & predictable environment
- To enjoy meaningful activities to fill each day
- To be out of doors on a regular basis
- To have physical contact including hugging, caressing and handholding
- To be with persons who know one's life story, including cultural and religious traditions
- To be cared for by individuals well-trained in dementia care

*Source: *Journal of Alzheimer's Care & Related Disorders*

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Guiding Principle #4: Recognize The
Unique Needs of the Individual



[Don't try to fit a square peg in a round hole....]

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Rules of Planet Alzheimer's*



- Never argue
- Logic and reason do not exist
- Lying IS acceptable
- You are not who YOU think you are – you are who THEY think you are
- Never take anything personally
- Old memories are best
- Learning to do something new is not important
- Being loved and accepted at all times is
- Have no expectations
- Take advantage of the shuttle back to Earth as often as possible

*Source: *Welcome to Planet Alzheimer's – Candace A. Stewart*

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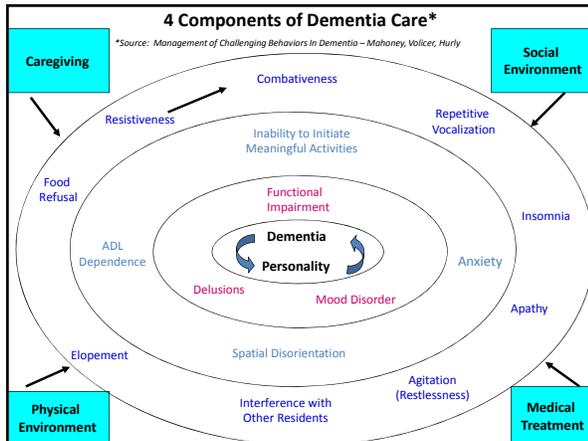
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Behavior Management in Alzheimer's Care

- Behaviors are the sign of an unmet need
- If we can figure out the cause of the unmet need, we can better keep our loved one safe and comfortable (reduce undesirable or harmful behaviors)
- It's always better to have a prevention strategy than waiting for the behavior to occur
- We look to the 4 Components of Dementia Care for clues to unmet needs



Medical Environment Checklist

Check	Medical Treatment
	Is there any indication of pain?
	Is there evidence of fatigue? Have sleep cycles been interrupted?
	Has there been a change in mobility or flexibility?
	Are they getting enough exercise?
	Could it be a side effect of medication? Medication change? Too many meds?
	Could they have been injured in a recent fall?
	Have there been any changes in their eating habits?
	Are they properly hydrated?
	Are they having regular bowel movements? UTI?
	Could there be a change in any of the senses (vision, hearing, etc.)?
	Remember, not all symptoms are dementia-related. Could they be part of a pre-existing or new co-medical condition?
	Could it be an infection? Allergies, cold or flu?
	Did we make the necessary adaptations for an 85-year-old client?

Physical Environment Checklist

Check	Physical Environment
	Is there enough light? Does it create shadows or reflections? Are there drastic light changes between living spaces?
	Are there too many sounds (TV & radio)? Are there sudden noises? New or unexpected sounds?
	Are there cooking smells? Odors from cleaning supplies?
	Are clothes too tight or too loose? Is clothing appropriate for the season? Are fabrics that touch skin soft?
	Is the room too hot? Too cold?
	Do they have access to see outdoors? Time to be outdoors? Do they receive enough natural light?
	Is favorite furniture safe & accessible? (Remember: they are 85 years old)
	Are all used spaces safe & accessible? Area areas most used clutter free & simplified?
	Bathroom easily seen & accessible? Is adaptive equipment installed correctly & functioning?
	Are pathways free of clutter? Are there color or texture changes in flooring between used spaces?

Social Environment Checklist

Check	Social Environment
	Is there a set, relaxed rhythm to each day, or does the schedule change?
	Are they napping during the day? Have sleep cycles been interrupted?
	Do they understand the TV program? Does the action seem to increase agitation? Do they lose track of story during commercials?
	Do they react to their favorite music? Do they find certain music soothing?
	Do they change spaces during the day? Do you maximize the use of favorite areas?
	Are they able to take a bath? Can you assist without resistance?
	Do they keep regular eating times?
	Has their schedule been changed? Have new people or pets been introduced?
	Have they moved to a new living arrangement?
	Could they be bored? Do they have enough to do?
	Do you do activities together? Do you spend time holding hands? Do you hug?
	Does family visit? Do friends drop by? Do you go out to eat or have coffee?
	Is time spent in spiritual pursuit if part of their normal schedule? Scripture? Hymns?
	Have there been changes in their ability to perform a meaningful activity?

Art of Caregiving Checklist

Check	Art of Caregiving
	Do you ask if they remember who you are? Do you tell them your name & theirs?
	Do you reassure them when you leave the room?
	Do you correct them when they were wrong? Did you argue?
	Do you redirect them to a more pleasant activity?
	Do you show your frustration? Do you take it personally?
	Do you take a few minutes to reminisce and hold hands?
	Do they resist bathing? Do you try again later?
	Do you laugh together?
	Do you stay "in the moment" with them? Were you totally "present"?
	Do you schedule toileting to avoid accidents?
	Do you reduce distractions during mealtime?
	Do you take activity away because they could not perform all steps?
	Do you reduce the risk of falls?
	Do you quiz them? Ask them to remember?
	Do you tell them that you love them?

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Communication Is The Most Powerful Tool



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Communication Tips

- Create a physical environment that facilitates good communication
- Understand the person's desire to communicate
- Treat the person as an adult
- Listen for/respond to emotional needs



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Communication Tips

- Non-verbal communication is powerful
- Do not take the person too literally
- Use repetition
- Do not argue or confront
- Screen out troubling messages or news
- Use positive language
- Employ humor in communication
- Do most of the work
- Exit well



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Skills for Success: Redirecting (Handling Agitation)

- Join the person in time, place and event
- Acknowledge the emotion
 - Help them understand you understand how they feel
- Agree: never reason or argue with the person
- Reassure them that you are with them
- Redirect attention or focus

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Scenario 1

- During a meal your mother refuses to eat and says, "You are trying to poison me!"

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Scenario 1

- Try answering, "I understand if you are feeling afraid, I want you to know I would never let anything bad ever happen to you. You are safe with me. Let's have some [meatloaf] together and you can tell me about the time you went to [vacation destination]."

Scenario 2

- Your father believes he is still at work. He treats you like his employee and tells you he needs the paperwork finished by the end of the hour.

Scenario 2

- Try saying, " You really run a tight ship around here. I guess that's what makes such a great boss. I will be sure to get the papers to you, but I need help. Can you assist me?"

Scenario 3

- You are assisting your husband getting dressed when he suddenly shouts, "Get away from me! You are not my wife!"

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Scenario 3

- “You must love your wife very much. I can tell by the way you talk about her. Why don’t you tell me about your wedding day?”

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Scenario 4

- Your client say, “You stole my money! Give it back!”

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Scenario 4

- “Oh no, your money is missing? I can see why you are upset. Well, don’t worry because I am going to help you look for it.”

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Skills for Success: Keeping the Individual “Plugged In”

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A Light Bulb As Metaphor



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An Individual With Alzheimer’s: Like A Light Bulb

- Fragile
- Must be protected
- Potential to illuminate
- Must be plugged in



...with one big difference...

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How Can We Keep an Individual With Alzheimer's "Plugged In?"



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Prompting: A Simple Way to Plug In

- Will you please hold this wash cloth?
- Let's go to the window and look at the birds.
- Why don't you taste the mashed potatoes?
- Which blouse would you like to wear today – the pink one or the blue one?
- Let's hold hands.
- Tell me about the day you married Dad.
- Tell me about your time in the Navy. What was the name of your ship?

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Simple Activities to "Plug In"

- Sorting laundry
- Cooking
- Setting the table
- Looking at old photos
- Going for a walk

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What makes a good day good? Moments of Joy



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Moments of Joy



