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Connecting the Pieces of the Dementia Care Puzzle

It's All In Your Approach!

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Objectives:

1. Describe the five sensory input and processing systems highlighting the dominant role of vision.
2. Discuss the impact of changing sensory awareness and processing as dementia progresses.
3. Compare and contrast “normal” aging versus “not normal” aging
4. Understand the value of positive reinforcement to promote well-being throughout the disease process.

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Introduction: Beliefs

- The relationship is MOST critical
NOT the outcome of one encounter
- We are a KEY to make life WORTH living
- People living with **Dementia** are Doing the BEST they can
- We must be willing to CHANGE ourselves

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5 Senses How Humans Take In Data



1. What you see
2. What you hear
3. What you feel/ touch
4. What you smell
5. What you taste

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Visual Data



The most powerful sensory input.

People with dementia pay more attention to what they see than what they hear.

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Auditory Data



What do we often do wrong?

Care partners like to talk.

The person with dementia is focused on how we look visually and they are not processing the content.

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Make a Note



- No touching until you've done a visual/verbal
- Don't do "to" someone...do "with" someone
- Dementia robs skill before robbing strength
- Use "hand under hand" to support

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NORMAL Aging

- Can't recall a word. Describe the word to get it to pop up.
- Give people time to process information. Go more slowly.
- Slower to think.
- Slower to do.
- May hesitate more.
- More likely to look before they leap.
- Will know the person, but not find the name.
- May pause when word finding
- New data reminds me of old data

NOT Normal Aging

- Unable to think the same
- Unable to do as before
- Unable to get started on a task
- Will get stuck in a moment of time
- Unable to think things out
- Unable to successfully place a person
- Words won't come even with visual, verbal, or touch cues
- Confused between past and present
- Personality and/ or behaviors will be different

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REALIZE ... 

*It Takes TWO to Tango ...
or two to tangle...*

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Dementia: What is It? 

It is BOTH

- a chemical change in the brain

AND

- a structural change in the brain

This means...

- It may come and go.
- "Sometimes they can and sometimes they can't."

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Dementia: What Changes 

- Structural changes –permanent
 - Cells are shrinking and dying
- Chemical changes - variable
 - Cells are producing and sending less chemicals
 - Can 'shine' when least expected – chemical rush

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Dementia Equals...



Brain Failure

The person's brain is dying

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**DEMENTIA
does not =
Alzheimer's
does not =
"Memory Problems"**

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Four Truths About Dementia



1. At least 2 parts of the brain are dying
2. It is chronic and can't be fixed
3. It is progressive and will get worse
4. It is terminal

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Is MCI always Dementia?

- Could be a form of DEMENTIA
- Symptom of another health condition
- Medication side-effect
- Hearing loss or vision loss
- Depression
- Delirium
- Pain-related

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Mimics of Dementia Symptoms

Depression <ul style="list-style-type: none">• can't think• can't remember• not worth it• loss of function• mood swings• personality change• change in sleep	Delirium <ul style="list-style-type: none">• swift change• hallucinations• delusions• on & off responses• infection• toxicity• dangerous
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If You Notice Changes...

You Should

- Get an assessment
- Go see the doctor

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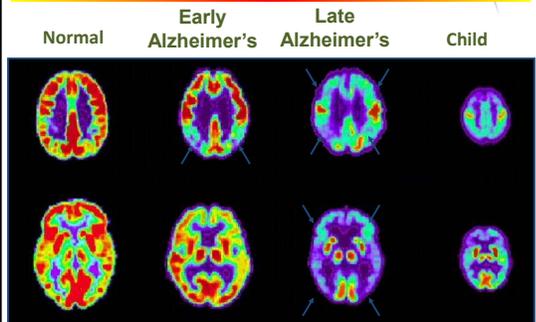
Dementia...



- It changes everything over time
- It is NOT something a person can control
- It is NOT the same for every person
- It is NOT a mental illness
- It is real
- It is very hard at times

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Positron Emission Tomography (PET) Alzheimers Disease Progression vs. Normal Brains



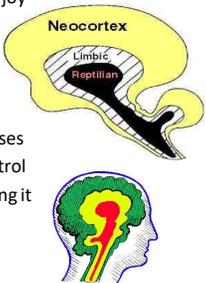
G. Small, UCLA School of Medicine.

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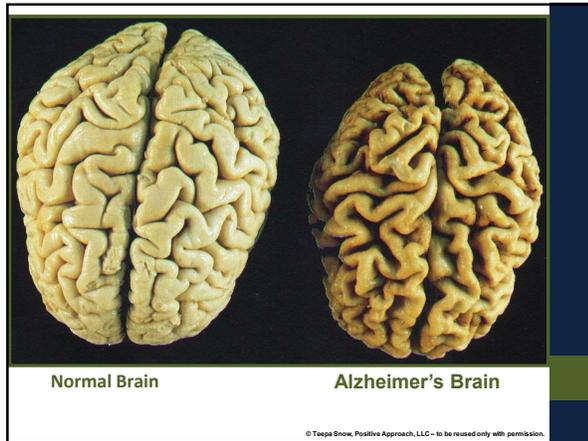
Primitive Brain is in Charge of:



- Survival –
 - Autonomic protective – fright, flight, fight
 - Pleasure seeking – needing joy
- Thriving – Running the Engine
 - Vital systems
 - Wake-sleep
 - Hunger-thirst
 - Pain awareness and responses
 - Infection recognition & control
- Learning New and Remembering it
 - Information
 - Places Awareness
 - Time Awareness



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Brain Atrophy



- The brain actually shrinks
- Cells wither then die
- Abilities are lost
- With Alzheimer's area of loss is fairly predictable
- BUT the experience is individual...



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This slide features a title 'Brain Atrophy' and a list of five bullet points. To the right of the text is a small icon of a feather. Below the text is a small image showing two brains, similar to the one in the first slide, illustrating the difference in size between a normal brain and an atrophied brain.

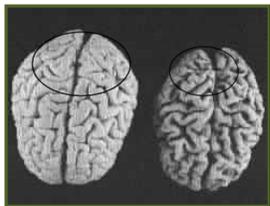
Vision Center – BIG CHANGES



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This slide has a title 'Vision Center – BIG CHANGES' and a feather icon. Below the title is a large image of two brains side-by-side. Red circles are drawn around the posterior regions of both brains, highlighting the area of the visual cortex. The Alzheimer's brain shows a noticeable reduction in the size of this region compared to the normal brain.

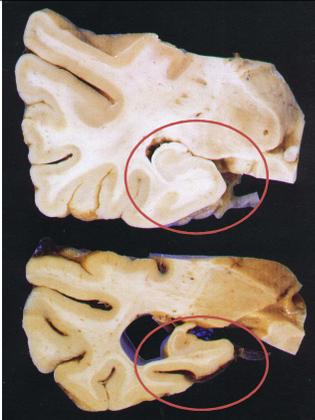
Vision



- Losses**
 - Edges of vision – peripheral field
 - Depth perception
 - Object recognition linked to purpose
 - SLOWER to process – scanning & shifting focus
- Preserved**
 - ‘See’ things in middle field
 - Looking at... curious

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Hippocampus BIG CHANGE

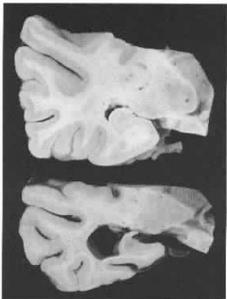


Learning & Memory Center

- Way finding
- Time Awareness
- Learning & Memory

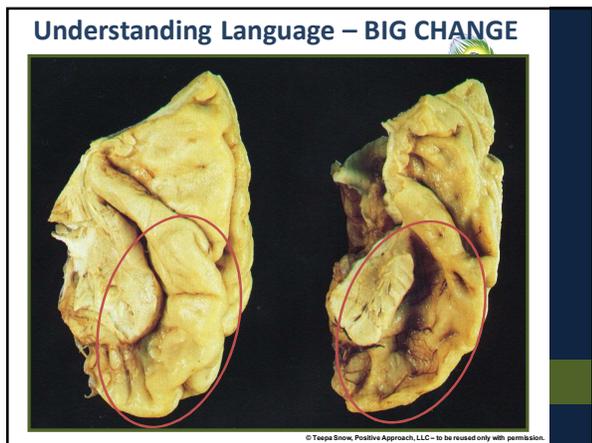
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Memory Loss



- Loss**
 - Immediate recall
 - Attention to selected info
 - Recent events
 - Relationships
- Preserved Ability**
 - Long ago memories
 - Confabulation!
 - Emotional memories
 - Motor memories

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Language

Normal

Alzheimer

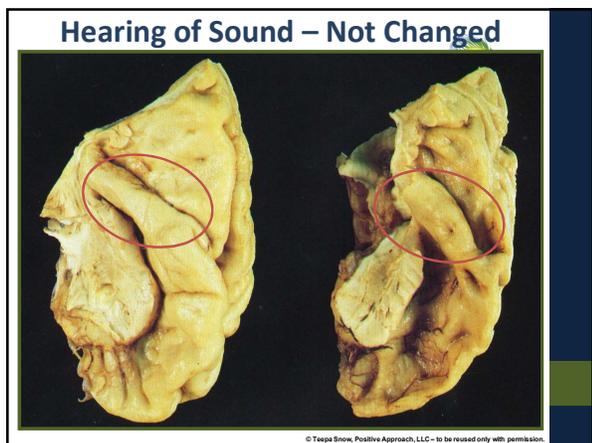
Loss

- Can't find the right words
- Word Salad
- Vague language
- Single phrases
- Sounds & vocalizing
- Can't make needs known

Preserved Ability

- Singing
- Automatic speech
- Swear words, sex talk, forbidden words

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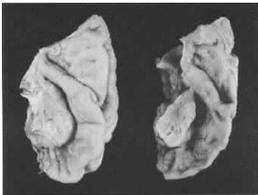
Understanding

Loss

- Can't interpret words
- Misses some words
- Gets off target

Preserved Ability

- Can get facial expression
- Hears tone of voice
- Can get some non-verbals
- Learns how to cover



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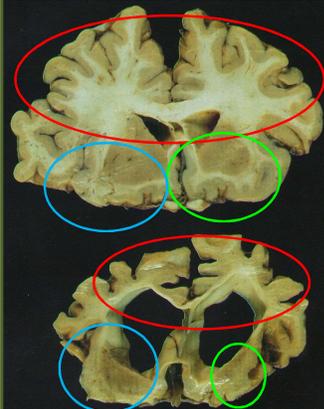




Executive Control Center

- Emotions
- Behavior
- Judgment
- Reasoning

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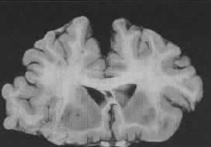
**Sensory Strip
Motor Strip
White Matter
Connections
BIG CHANGES**

**Automatic Speech
Rhythm – Music
Expletives
PRESERVED**

**Formal Speech &
Language
Center
HUGE CHANGES**

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Sensory Changes



Normal

Loss

- Awareness of body and position
- Ability to locate and express pain
- Awareness of feeling in most of body

Preserved Ability

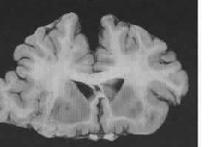
- 4 areas can be sensitive
- Any of these areas can be hypersensitive
- Need for sensation can become extreme



Alzheimer

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Self-Care Changes



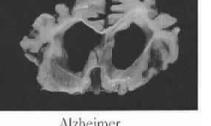
Normal

Loss

- initiation & termination
- tool manipulation
- Sequencing

Preserved Ability

- motions and actions
- the doing part
- cued activity



Alzheimer

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Top 10 unmet needs!



Physical	Emotional
<ul style="list-style-type: none">•Hungry or Thirsty•Tired or Over-energized•Elimination – need to/did•Temperature – too hot/cold•IN PAIN!!!<ul style="list-style-type: none">- Joints - skeleton- Inside systems (head, chest, gut, output)- Creases or folds & skin- Surfaces that contact other surfaces	<ul style="list-style-type: none">•Angry•Sad•Bored•Scared•Lonely

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The Basics for Success



- Be a Detective NOT a Judge
- Look, Listen, Offer, Think...
- Use Your Approach as a Screening Tool
- Always use this sequence for CUES
 - Visual - Show
 - Verbal - Tell
 - Physical - Touch
- Match your help to remaining abilities

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Build Skill



- Positive Physical Approach™
- Supportive Communication
- Consistent & Skill Sensitive Cues
 - Visual, verbal, physical
- Hand Under Hand™
 - for connection
 - for assistance
- Open and Willing Heart, Head & Hands

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Approach Matters



Use a consistent Positive Physical Approach™

- Pause at edge of public space
- Gesture and greet by name
- Offer your hand and make eye contact
- Approach slowly within visual range
- Shake hands and maintain Hand-Under-Hand™
- Move to the side
- Get to eye level & respect intimate space
- Wait for acknowledgement

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Supportive Communication

Make a connection

- Offer your name – “I’m (NAME)... and you are...”
- Offer a shared background – “I’m from (place) ...and you’re from...”
- Offer a positive personal comment – “You look great in that” or “I love that color on you...”

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Emotional Communication

Validate emotions

- EARLY – “It’s really (label emotion) to have this happen” or “I’m sorry this is happening to you”
- MIDWAY – Repeat/reflect their words (with emotion)
 - LISTEN for added information, ideas, thoughts
 - EXPLORE the new information by ‘watching and listening’ (wonder what they are trying to communicate)
- LATE – Check out their ‘whole’ body –
 - Observe face, posture, movement, gestures, touching, looking
 - Look for NEED under the words or actions

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Keep it SIMPLE



- USE VISUAL combined VERBAL (gesture/point)
 - “It’s about time for...”
 - “Let’s go this way...”
 - “Here are your socks...”
- DON’T ask questions you DON’T want to hear the answer to...
- Acknowledge the response/reaction to your information...
- LIMIT your words – SIMPLE is better always
- Wait, Pause, Slow Down

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When Words Don’t Work Well



Hand-under-Hand™

- Uses established nerve pathways
- Allows the person to feel in control
- Connects you to the person
- Allows you to DO with not to
- Gives you advance notice of ‘possible problems’
- Connects eye-hand skills
- Use the dominant side of the person



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Use Hand-Under-Hand™



- Connecting – comforting and directing gaze
- Guiding and helping with movement
- Getting eye contact and attention
- Providing help with fine motor
- Offering a sense of control, even when you are doing almost everything



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Three Reasons to Communicate

- Get something DONE
- Have a conversation
- Help with distress

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Getting the person to DO Something

Form a relationship FIRST
Then Work on Task Attempt

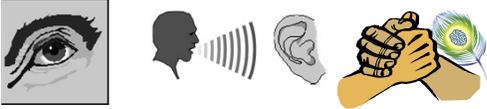
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Connect

- 1st – Visually
- 2nd – Verbally
- 3rd – Physically

- 4th – Emotionally
- 5th – Personally – Individually - Spiritually

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To Connect

Use the Positive Physical Approach

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Human Beings Have **THREE ZONES** of Awareness of Others

- Public Space – 6 ft away or more
- Personal Space – 6 ft to arm's length
- Intimate Space – within arm's reach

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Typical Use of Space

- Public Space - Visual Interactions & Awareness
- Personal Space – Conversations & Friendship
- Intimate Space – Intense Physical Closeness

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Your Approach



- Use a consistent positive physical approach
 - pause at edge of public space
 - gesture & greet by name
 - offer your hand & make eye contact
 - approach slowly within visual range
 - shake hands & maintain hand-under-hand
 - move to the side
 - get to eye level & respect intimate space
 - wait for acknowledgement

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Step 1



- Pause at the Edge of Public Space
 - Stop moving at 6 ft
 - Let the person NOTICE you in public space
 - Acknowledge the person's OWNERSHIP of personal space
 - Respect their space!

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Step 2



- Greet
 - Bring flat, open palm up near face
 - Visually cue to look at you
 - Say "Hi!" and use preferred name, if known
 - Verbally cue to look at you
 - Look Friendly
 - Smile
 - Make eye contact

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Step 3



- Offer you hand in greeting
 - Seek permission to enter PERSONAL SPACE
 - SHOW the person what you want to do
- Watch for the person’s reaction/response
 - If there is hesitation or withdrawal
 - STAY in PUBLIC space
 - Turn your body SIDEWAYS – supportive stance
 - Kneel or sit down
 - See what happens next – if no better, hold back

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Step 4



- Move Slowly toward the person
 - While offering your hand in greeting
 - Smile and look friendly
 - 1 second = 1 step
 - Respect SLOWED processing time
 - Decreased ability to do two things at one time

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Step 5



- Move into SUPPORTIVE stance
 - Shift toward the right side – hand shake side
 - Turn your TRUNK sideways to the person
 - Stay at ARM’S length
 - Keep your face & chest back

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Step 6



Switch into the **Hand-under-Hand™ (HuH™)**

- position from a normal handshake
 - Provides protection for the person you are helping
 - Keeps you from hurting their wrist, arm, or fingers
 - Provides protection for you
 - Keeps the person from squeezing your knuckles
 - Keeps the person from hitting or grabbing you
 - CONNECTS you with the person you are helping
 - Helps direct gaze – eye-hand coordination
 - Pressure in the palm is calming

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Hand-under-Hand™ (HuH™)



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Hand-under-Hand™:
protects aging, thin, fragile, forearm



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High Risk



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Step 7



- Get Low – Get to the person's level
 - Sit down OR Get down (kneel or squat)
 - Respect INTIMATE space
 - Allow eye contact with limited visual field
 - Get focus on your face not your chest or middle

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Step 8



- Wait for a response or acknowledgement
 - Make sure you have a CONNECTION before you start your message
 - You have 3 points of connection – Need MORE?
 - Visual – eye contact
 - Verbal – friendly voice
 - Touch – hand-under-hand
 - Begin to add two more
 - Emotional – match their emotion
 - Individual – say something personal – use name

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Your Approach



- Use a consistent positive physical approach
 - pause at edge of public space
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 - get to eye level & respect intimate space
 - wait for acknowledgement

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Positive Physical Approach™

(PPA™)



To the tune of Amazing Grace

Come to the front, Get low
 Get to the side, Get low
 Offer your hand, Call out their name
 Then wait.....
 If you will try, then you will see
 How different life can be
 For those you're car-ing for.

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For ALL Communication

If what you are trying is NOT working...

- STOP
- Back off
- THINK IT THROUGH...
- Then, re-approach
- And try something slightly different

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Care Partners Need To...

- Take care of yourself
- Understand the symptoms and progression
- Build skill in support and caregiving
- Build skill in communication and interactions
- Understand 'the condition' of brain change
- Identify and utilize local resources
- Set limits for yourself

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How You Look At Dementia Matters!

- It is NOT all about loss
- It is NOT "untreatable"
- It is NOT unpredictable
- Behaviors DON'T come out of nowhere
- Dementia DOESN'T just affect the person with the disease – it impacts all of us

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Dementia Can Be Treated

- With knowledge
- With skill building
- With commitment
- With flexibility
- With practice
- With support
- With compassion


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People living with dementia need care partners to think about and act on what they want, need, and think.

Watch and Observe

- What they show you- how they look
- What they say – how they sound
- What they do – physical reactions

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Changing the Culture of Dementia Care One Mind at a Time

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Dementia Skilled
Dementia Competent

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