

Changing the Culture of
Dementia Care
One Mind at a Time

Positive
Approach

GEMS[®]
Dementia **Aware**
Dementia **Knowledgeable**
Dementia **Skilled**
Dementia **Competent**

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Managing Behaviour Starts With Yourself

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So, What is Dementia?

- It is not part of normal aging! It is a disease!
- It is more than just forgetfulness, which is part of normal aging
- It makes independent life impossible, eventually
- It changes everything over time
- It is not something the person can control
- It is not always the same for every person
- It is not a mental illness
- It is real
- It is hard at times

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What is Dementia?

It is both
 a chemical change in the brain
 and
 a structural change in the brain

So...

Sometimes they can and sometimes they can't

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Why Do 'Things' Happen?

Everything is affected:

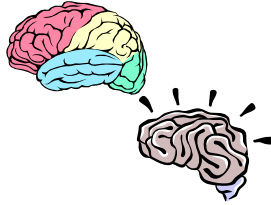
- Thoughts
- Words
- Actions
- Feelings

It is progressive:

- More brain dies over time
- Different parts get hit
- Constant changing

It is variable:

- Moment to moment
- Morning to night
- Day to day
- Person to person



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Dementia is often predictable:

- Specific brain parts
- Typical spread
- Some parts preserved

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Example of Challenges:

No financial or health care POA

Losing important things

Getting lost

Unsafe task performance

Repeated calls and contacts

Refusing

'Bad mouthing' you to others

Making up stories

Resisting care

Swearing and cursing

Making 911 calls

Mixing day and night

Shadowing

Eloping or wandering

No solid sleep time

Getting 'into' things

Threatening caregivers

Undressing

Being rude

Feeling 'sick'

Striking out at others

Falls and injuries

Infections and pneumonias

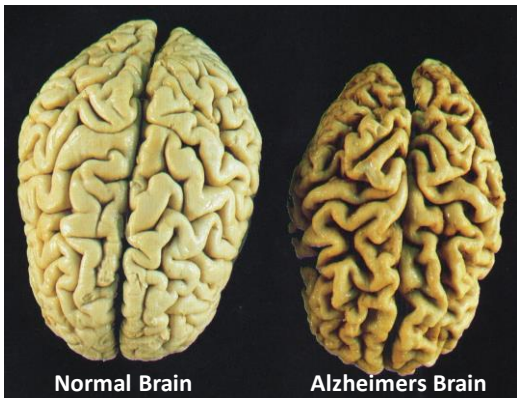
Seeing things and people

Not eating or drinking

Contractures and immobility

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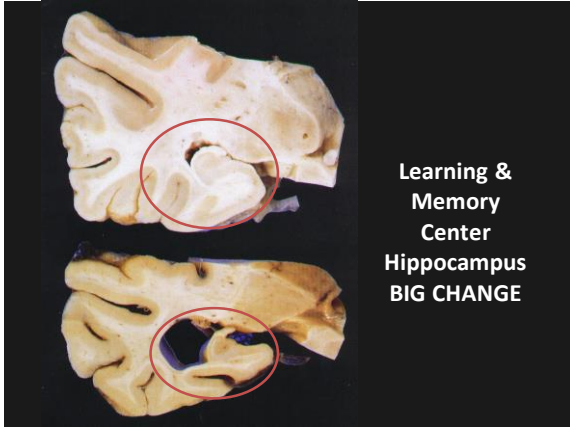
Normal Brain

Alzheimers Brain

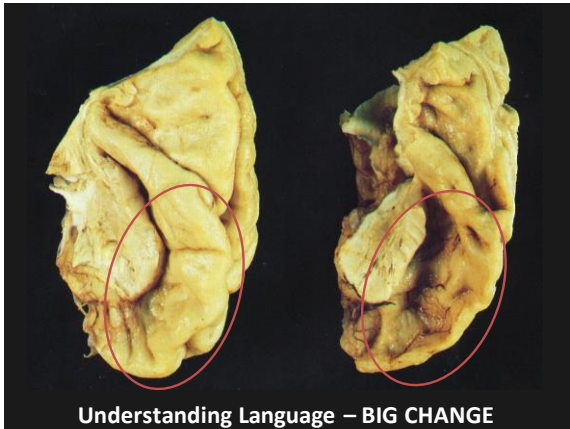
Used with permission from *Alzheimers: The Broken Brain*, 1999 University of Alabama

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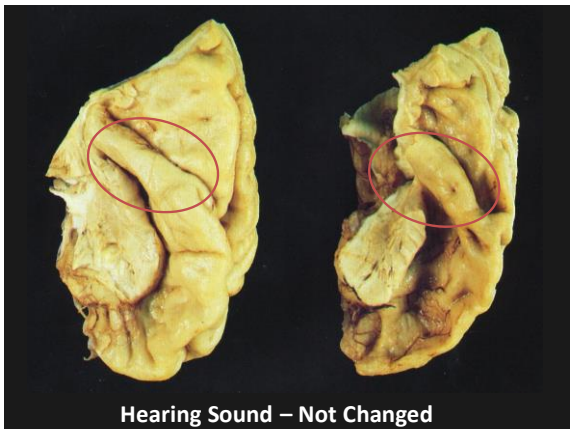
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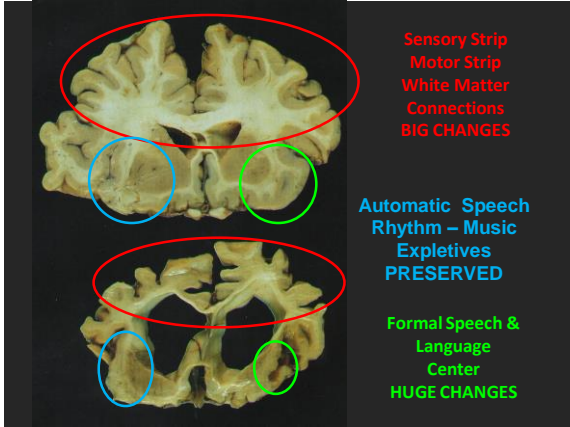
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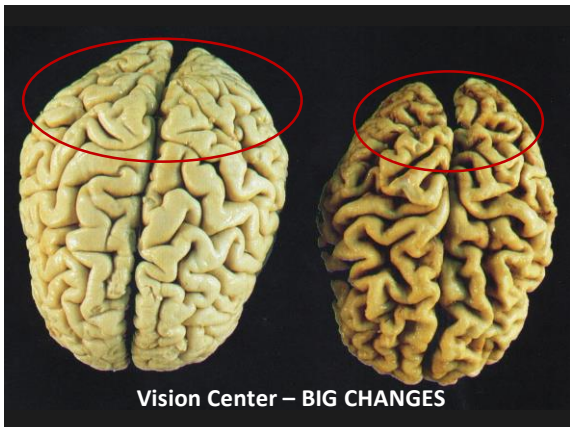
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Six Pieces of the Puzzle:

1. Personal history and preferences
2. Level and type of dementia
3. Other health conditions and sensory losses
4. Environmental conditions
5. Care partner approach and behaviors
6. The day and how it all fits together

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The First Piece of the Puzzle:

The person and who they have been:
personality, preferences and history

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Knowing the Person:

- History
- Values and beliefs
- Habits and routines
- Personality and stress behaviors
- Work and family history
- Leisure and spiritual history
- 'Hot buttons' and comforts

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Some 'stuff' we think that people do on purpose is really just who they are

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Personal Preferences Matter:

- We like what we like!
- With dementia, the 'likes' can change
- The challenge is to honor what is important but change what is needed
- Our willingness to meet the person's changing needs is essential
- Changes are made harder by our sense of loss and grief

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The Second Piece of the Puzzle:

The Level and Type of Dementia

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Progression of Dementia: The GEMS®



Sapphires: True Blue, Healthy Brain

Diamonds: Clear and Sharp, Routines and Rituals Rule, Change is Hard

Emeralds: Green/On the Go with Purpose, Naturally Flawed

Ambers: Caught in a Moment of Time, Caution Required

Rubies: Deep and Strong, Others Stop Seeing What is Possible

Pearls: Hidden in a Shell, Beautiful Moments to Behold

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Sapphires



- Us on a good day
- Clear and true to ourselves
- May feel 'blue' over changes
- Some are 'stars' and some are not
- Can typically choose our behavior
- May have other health issues that affect behaviors
- Recognize life experiences, achievements and values
- Can follow written info and hold onto it

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Diamonds



- Sharp, hard, rigid, inflexible, can cut
- Many facets, still often clear, can really shine
- Are usually either Joiners or Loners
- Can complete personal care in familiar place
- Usually can follow simple prompted schedules
- Misplaces things and can't find them
- Resents takeover or bossiness
- Notices other people's misbehavior and mistakes
- Vary in lack of self-awareness
- Use old routines and habits
- Control important roles and territories, use refusals

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Emeralds:



- Changing color
- Not as clear or sharp, more vague
- On the go, need to 'do'
- Flaws may be hidden
- Time traveling is common
- Are usually Doers or Supervisors
- Do what is seen, but miss what is not seen
- Must be in control, but not able to do it correctly
- Do tasks over and over, or not at all

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Ambers:



- Amber Alert- Caution!
- Caught in a moment
- All about sensation and sensory tolerance, easily over or under-stimulated
- May be private and quiet or public and noisy
- No safety awareness
- Ego-centric
- Lots of touching, handling, tasting, mouthing, manipulating
- Explorers, get into things, invade space of others
- Do what they like and avoid what they do not like

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Rubies:



- Hidden depths
- Major loss of fine motor finger and mouth skills, but can do gross motor skills like walking, rolling, rocking
- Comprehension and speech halted
- Wake-sleep patterns very disturbed
- Balance, coordination, and movement losses
- Eating and drinking patterns may change
- Tends toward movement unless asleep
- Follows gross demonstration and big gestures for actions
- Limited visual awareness
- Major sensory changes

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Pearls:



- Hidden in a shell: still, quiet, easily lost
- Beautiful and layered
- Spends much time asleep or unaware
- Unable to move, bed or chair bound, frequently fall forward or to side
- May cry out or mumble often, increases vocalizations with distress
- Can be difficult to calm, hard to connect
- Knows familiar from unfamiliar
- Primitive reflexes
- The end of the journey is near, multiple systems are failing
- Connections between the physical and sensory world are less strong but we are often the bridge

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The Third Piece of the Puzzle:

Other medical conditions
Psychological or psychiatric conditions
Sensory status: vision, hearing, sense of touch, balance, smell, taste

Medications
Treatments



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The Fourth Piece of the Puzzle:

The Environment:
Physical
Sensory
Social



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Supportive Environments: The 3 Positive P's

1. **P**hysical Environment
2. **P**eople: the ways they act and respond
3. **P**rogramming

Find a balance, not too much or too little

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The Fifth Piece of the Puzzle:

People and Their Behaviors:

- Care Partners
- Family Members
- Friends
- You!

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What Shouldn't We Do?

- Argue
- Make up stuff that is not true
- Ignore problem behaviors
- Try a possible solution only once
- Give up
- Let them do whatever they want to
- Force them to do things

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So What Should We Do?

Remember who has the healthy brain!

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The Sixth Piece of the Puzzle:

The Day and How it All Fits Together:

Daily routines and programming
Filling the day with valued engagement
GEMS® state programming

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Examples of Meaningful Activities:

- **Productive Activities:** sense of value and purpose
- **Leisure Activities:** having fun and interacting
- **Self-Care and Wellness:** personal care of body and brain
- **Restorative Activities:** re-energize and restore spirit

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Now that you are aware
of the **Six Pieces of the
Puzzle**, reframe
'problem behaviors'
as 'unmet needs'

Get interested, excited,
and be challenged!

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 **Top Five Unmet Needs:** 

Physical Needs:

- Hydration and Nourishment
- Wake-sleep and active-rest cycles
- Elimination: all forms
- Find Comfort: 4Fs 4Ss
- Pain-free:
 - Physical – body
 - Emotional – relationships
 - Spiritual – belonging/purpose

**Signals of Emotional
Distress:**

- Angry
- Sad
- Lonely
- Scared
- Bored – Lacking
Purpose

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Breathe!!!

Take a deep breath in
Blow it all the way out
Take another breath in
Blow it out
Take one final breath in and
Sing it out....

Feel what happened to you
Look at what happened to the people
around you
Think about how and when you might do
this

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Let Go:

How it 'used to be'

How it 'should be'

How you 'should be'

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Identify:

What you're good at...and what you're not

Who can help...and how they can help

What really matters

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**What you leave behind is not
what is engraved in stone
monuments,
but what is woven into the
lives of others**

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I Will Change!

(to the tune of
This Little Light of Mine)

By Teepa Snow

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I am gonna meet and greet
Before I start to treat
I am gonna meet and greet
Before I check your feet
I am gonna meet and greet
Before I help you eat

How I start sets us up to succeed!

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No more just "Getting' it Done"
I'm gonna DO with you
No more just "Getting' it Done"
I'm gonna help you thru
No more just "Getting' it Done"
We're gonna work, we two

Cause if I do it ALL, we BOTH LOSE!

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I'm gonna laugh and dance with you
Not just watch and frown
I'm gonna laugh and dance with you
Not just stand around
I'm gonna laugh and dance with you
We'll really go to town

For the POWER of JOY I have found!

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Friends!

- Friends, I will remember YOU
- Think of you and pray for you.
- And when another day is through
- I'll still be friends with you!

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