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Best Practices in Dementia Care

Quiz Time!
- What do we know?
- What do we think we know?
- What don’t we know?
- What surprised us most?
- What can we do about it?

Question #1:
Senile Dementia and Alzheimers are two different words for the same condition
a. True
b. False
c. I don’t know
About 90-95% of the general public think

Better Answer:
Having dementia does not equal and is more than just Alzheimer's. Having dementia does not equal and is more than just memory problems.

Why is Dementia Different as the Journey Happens?

- It typically takes a long time.
- The person will change, and change, and change,...
- The person is being changed, even as they remain.
- Others are evolving and changing over the journey.
- How it was is not how it is.
- Change can happen day to day, minute to minute, or may not happen for months... and then it does!
- What should happen/work, doesn't always.
Question #2:

About how many types, forms, or causes of dementia are there?

a. 2-3
b. 5-10
c. 20-40
d. Over 100
e. I have no idea
Possible Value of Animal Fluency Screening:
- Name as many animals as you can
- Give one minute: don’t highlight time limit
- Count each animal named: not repeats

- Use it to establish a baseline
  - Normal/Not Normal old guidelines: 12 normal for > 65 and 18 for < 65
  - New: Compare you to you over time - quick notice of a change

Question #3:
What is one of the most common losses of ability someone will experience when they get any form of dementia?
- a. Loss of ability to hear sound
- b. Loss of ability to recognize familiar voices as familiar
- c. Inability to know another person is upset by noticing their tone of voice
- d. Loss of formal language skills – vocabulary, comprehension, speech production
- e. I have no idea

Understanding Language – Big Change

Changes in Language Skills
- Vocabulary
- Comprehension
- Speech Production
Question #4:

What is the how much of your brain tissue will you typically lose by the end of the condition?

a. About 95%
b. About 65%
c. About 50%
d. About 30%
e. I don’t know

For all that is lost, some remains!

- 1/3 of brain remains
- Know what still works
- Know how we support in areas of loss
**Normal Brain**

**Alzheimers Brain**

**Connections:**

- **Sensory Strip**
- **Motor Strip**
- **White Matter**

**Big Changes**

**Automatic Speech**

**Rhythm – Music**

**Expletives:**

- **Preserved**

**Formal Speech and Language Center:**

**Huge Changes**

**Executive Control Center Changes:**

- Being logical, reasonable, rational
- Controlling impulses
- Making decisions
- Initiating-sequencing-terminating-transitioning
- Being self-aware
- Seeing other perspectives
Hippocampus
Big Changes:
- Learn and remember
- Way-finding
- Passage of time

Executive Control Center:
- Emotions
- Behavior
- Judgment
- Reasoning

Storage units - data
Wiring - connecting, bringing data in and sending data out
Question #5:
What is the first change with dementia?

a. The brain begins to shrink
b. The chemistry of the brain changes
c. The person’s personality changes
d. The person’s behavior changes
e. I don’t know

PET and Aging:

PET Scan of 20-Year-Old Brain  PET Scan of 80-Year-Old Brain

PET and Aging:

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

G. Small, UCLA School of Medicine.
Four Truths About Dementia:

1. At least 2 parts of the brain are dying - one related to memory and another part
2. It is chronic – can’t be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually

Question #6:
What is it called when you have dementia and continue to think you are as skilled as you were before, even though you are making mistakes now?

a. Anosognosia
b. Denial
c. Hippocampal damage
d. Confabulation
e. I really don’t know

Positron Emission Tomography (PET)
Alzheimer's Disease Progression vs. Normal Brains

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Question #7:
About what percentage of people under age 70 have some form or degree of active symptoms of dementia?

a. 1% - it is very rare
b. About 5-10%
c. About 25%
d. I don’t know

Question #8:
What is an effective treatment for dementia?

a. How we connect and respond to people who are living with the condition
b. There are pills people can take to slow the disease down
c. There is nothing that really helps
d. Exercise and eating right keeps it from getting worse
e. I don’t know

How Can We Become Better Care Partners?

- Let go of the past to be in the moment
- Go with their flow
- Be willing to try something new
- Be willing to learn something different
- Be willing to see it through another’s eyes
- Be willing to fail and try again
- Be a detective, not a judge
- Match your help to their remaining abilities
- Look, listen, offer, think
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
- Elop ing 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
- Mixing day and night
- Shadowing

So What Can You Do When Situations Are Challenging?

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
The First Piece of the Puzzle:

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

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

Some ‘stuff’ we think that people do on purpose is really just who they are
The Second Piece of the Puzzle:

The Level and Type of Dementia

GEMS®:

- Based on Allen Cognitive Levels
- Cognitive Disability Theory – OT based
- Creates a common language and approach to providing:
  - Environmental support
  - Caregiver support and cueing strategies
  - Setting expectations regarding retained abilities and lost skills
- Promotes graded task modification for success

Why Use The GEMS®?

- Until we begin to see the beauty and value in the person has at this point, we will never care for them as we should
- Gems are precious and unique, provide a common language and characteristics
- Use familiar concepts to talk about a difficult subject
- Focus on what is valued
- Allow us to get beyond the words ‘dementia’ and ‘Alzheimers disease’
- Open the door to talking about changes
- Allow us to speak in a ‘code’ to protect dignity
The GEMS® Progression of Dementia: Seeing What Remains

Sapphires – True Blue – Slower but Fine
Diamonds – Repeats and Routines, Cutting
Emeralds – Going – Time Travel – Where?
Ambers – In the Moment - Sensations
Rubies – Stop and Go – Big Movements
Pearls – Hidden in a Shell - Immobile

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

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
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

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

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
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

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

The Fourth Piece of the Puzzle:
The Environment:
Physical
Sensory
Social
The Fifth Piece of the Puzzle:

People and Their Behaviors
- Care Partners
- Family Members
- Friends
- You!

Getting The Person to Do Something:

Form a relationship first, then work on task attempt!

Positive Physical Approach™:
- Pause at edge of public space (6 feet)
- Gesture and greet by name
- Offer your hand and make eye contact
- Approach slowly within visual range
- Shake hands and then maintain Hand-under-Hand®
- Move to the side
- Get to eye level and respect intimate space
- Wait for acknowledgement
Hand-under-Hand® Assistance:

A Positive Approach
(To the Tune of Amazing Grace)
Come from the front
Go slow
Get to the side,
Get low
Offer your hand
Call out the name, then wait…
If you will try, then you will see
How different life can be.
For those you’re caring for!

Then, Connect Emotionally:
- 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.”
- Make a positive observation: “What beautiful flowers!” or “Great photo!”
Connecting Emotionally:
- Identify a common interest
- Say something nice about the person or their place
- Share something about yourself and encourage the person to share back
- Follow their lead and listen actively
- Use some of their words back to keep the flow going
- Remember it’s often the ‘first time’ for them, so expect repeats
- Use the phrase “Tell me about…”

Supportive Communication
- Repeat a few of their words with a question at the end
- Avoid confrontational questions
- Use just a few words
- Go slow
- Use examples
- Fill in the blanks
- Listen, then offer empathy: “Sounds like…” or “Seems like…” or “Looks like…”

Then, Get it Going!
- Give Simple and short information
- Offer concrete choices
- Ask for help
- Ask the person just to try
- Break the task down to single steps at a time
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

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

Using Music-Two Categories:

Quiet and Calm:
• Soothing rhythm
• Slow speed
• Deep pitch
• Quiet themes
• Personal background

Stimulate and Excite:
• Upbeat rhythms
• Faster speeds
• Higher pitches
• Fun/play themes
• Personal background
Know Your Residents:
Favorite artists
Favorite types of music
Favorite songs
Meaningful Songs
• Comfort songs
• Fun songs
• Life story songs
History with music, dance, performances
Dislikes
Volume preferences
Times of high action
Times of relaxation
Background sounds preferences
Seating/space preferences
Signals of enjoyment and distress

Now that you are aware of the Six Pieces of the Puzzle, reframe ‘problem behaviors’ as ‘unmet needs’
Get interested, excited, and be challenged!

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
**Bonus Question:**

Which message would you prefer if you had dementia?

a. You seem incompetent, let me help you
b. I am glad to see you. I could use your help.

c. There is clearly something wrong with you and I don’t know what to do
d. You are scaring me and I want you out of here
e. There is clearly something wrong with you and I am going to call the authorities for help