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When We Add a Second Dementia

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Speaker Disclosures:

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Objectives:

• Describe the differences seen in a person living with one versus more than one dementia
• Describe why we might want to explore differential diagnoses when there is already the presence of dementia and the use of Trauma Informed Care
• Use the Six Pieces of the Puzzle to identify:
  • 3 pieces we need to explore
  • 2 areas to try something new to engage using a tool: About Me
Why Bother Exploring a Complete Diagnosis?

Let’s watch Dixie…

Why Bother Exploring a Complete Diagnosis?

• Future planning
• Progression and prognosis
• Health
• Being in control
• Medications can make a difference (DIFFERENTLY for different dementias!) in quality of life
• Finances

Let’s watch Dixie again…

Now, what are we looking for?

Why do you think this is mixed picture?

Type into the chat what you are:
1. Seeing
2. Hearing, and
3. noticing physically
Dixie: What we noticed

See: …

Hear: Smacking lips, …

Touch: …

Pace: …

THIS is the How: It takes a team!

Six Pieces of the Puzzle
The Person

Past and Present
- Life story
- History
- Personality traits
- Preference
- Key values
- Joys and traumas
- Roles: Watcher, Talker, Doer
- Notable positive changes?
- Notable negative changes?

Personality traits
- Introvert or Extrovert
- Detail or Big Picture
- Logical/thinking or Emotional
- Planner (controlling) or In the Moment

Preferences...MATTER
- We like what we like, we want what we like
- Likes can change
- Appearance, routine, foods, music

Personal history
Health Changes

- Fuel and fluids
- Medications and supplements
- Emotion and psychological condition
- Sensory systems function
- Health beliefs of note
- Recent changes
  - Acute episode of illness
  - New/worsening chronic illness

Medical Condition & Sensory Status*:

- Fuel and fluids
- Other medical and psychiatric conditions
- Sensory status: vision, hearing, sense of touch, balance, smell, taste
- Medications and treatments

*May have ability to modify or attenuate some of these

Dementia (The 3 D's)

Delirium: dangerous and deadly
- Possible PAIN, infections, med changes/side effects, physiological changes (dehydration, blood chemistry, O₂ saturation)

Depression: treatable
- Most elders with depression describe themselves as having memory problems or somatic complaints
- Look for changes in appetite, sleep, self-care (sudden), pleasures, irritability, 'I can't take this'

Dementia
- Type(s)
- Stage
- Retained abilities
- Lost abilities
Brain Changes

Dementia
- Types(s)
- Awareness of changes?
- Delirium? Depression or Anxiety?

GEMS States
- Changed abilities
- Retained abilities
- Variability
- Onset and duration

Where do you begin?
Basic Hallmarks of...

Alzheimers:
- New info lost
- Recent memory worse
- Problems finding words
- Misspeaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months – 1 year
- Lasts 8-12+ years
Lewy Body Dementia:

- Movement problems, falls
- Visual hallucinations: animals, children, people
- Fine motor problems: hands, swallowing
- Episodes of rigidity, syncopy
- Nightmares or insomnia
- Delusional thinking
- Fluctuations in abilities
- Drug responses can be extreme and strange:
  - Can become toxic, can die, can become unable to move
  - Can have an opposite reaction

Latest Thinking about Lewy Body Treatment:

- Try AChIs: Start Low and Go Slow
- Then try Namenda early: Start Low and Go Slow
- Be very careful about anti-psychotic meds: not Haldol
- Balancing movement losses and aid to function: not working?
- Parkinson’s meds may/may not help movement but may make hallucinations and delusions worse
- Anti-depressants may be used to help anxiety, sleep, and depression but can increase confusion, movement drowing
- Sleep aids or anti-anxiety meds can cause paradoxical reactions

Vascular Dementia:

- Sudden changes: stepwise progression
- Other conditions: diabetes, hypertension, heart disease
- So, damage is related to blood supply/not primary brain disease: treatment can plateau
- Picture varies by person: blood/swelling/recovery
- Can have bounce back and bad days
- Judgment and behavior ‘not the same’
- Spotty loss in memory, mobility
- Emotional and energy shifts
Vascular Dementia:

CT Scan
White spots indicate dead cell areas:
Mini-strokes

Frontotemporal Dementias:

- Many types, typically Younger Onset
- Frontal: impulse and behavior control loss (not memory issues)
  - Says unexpected, rude, mean, odd things to others
  - Disinhibited: food, drink, sex, emotions, actions
  - OCD-type behaviors
  - Hyperorality
- Temporal: language loss
  - Can't speak or get words out
  - Can't understand what is said, sound fluent: nonsense words

FTDs:

- FvFTD: Frontal variant of FTD
- FTD: Frontotemporal lobe dementia
- TLD: Non-fluent aphasia
- TLD: Fluent aphasia
- CTE: Chronic Traumatic Encephalopathy
FvFTD:

- Mis-behavior
- Impulsivity
- Dis-inhibition
- Inertia
- Obsessive compulsive behaviors
- Inattention
- Lack of social awareness
- Lack of social sensitivity
- Lack of personal hygiene

Becomes sexually over-active or aggressive
Becomes rigid in thinking
Stereotypical behaviors
Manipulative
Hyper-orality
Language may be impulsive but unaffected or may be reduced or repetitive

FTD (Pick’s Disease):

Frontal Issues:
- Poor decision making
- Problems sequencing
- Reduced social skills
- Lack of self-awareness
- Hyper-orality
- Ego-centric
- Disinhibited: food, drink, words, actions
- OCD behaviors early
- Excessive emotions

Temporal Issues:
- Reduced attempts to talk
- Reduced content in speech
- Poor volume control
- Public use of ‘forbidden words’
- Sing-song speech
- Can’t understand others’ words

Temporal Lobe Non-Fluent Aphasia:

- Can’t name items
- Hesitant speech
- Not speaking
- Worsening of speech production over time
- Echolalia
- Misspeaking
- Word salad

Receptive inability
Other skills intact early
25% never develop global dementia
Temporal Lobe Fluent Aphasia:

- Has smooth delivery
- More nonsense words
- Word salad
- May think they make sense
- Expect rhythm back
- Fixates on a few phrases
- Chit-chats if enjoying company

Volume control varies: limited awareness of others’ needs

- There are frequently 1-2 ‘value words’ mixed into speech
- Picks up on ‘value words’ they hear – they then connect and want to talk more

Chronic Traumatic Encephalopathy:

- Caused by repeated head injuries or concussions – doesn’t happen to all
- Symptoms
  - Frontal lobe issues
  - Temporal lobe issues
  - Sometimes rapid progression into Alzheimer’s-type patterns
  - Sometimes rapid progression into FTD-type patterns

Alcohol-Drug Related Dementia:

- May be called Wernicke’s and Korsakoff’s syndrome

- Possibly caused by neurotoxicity and/or Vitamin B1 and thiamine deficiency
- Common Symptoms
  - Decreased ability to learn ‘new’
  - Decreased interest in valued activities, people, life
  - Impaired judgment and decision making
  - Emotional liability or apathy
  - Problems with balance and coordination
  - Problems with social control and behaviors
  - Problems with initiation and termination
Other Dementias:

- Genetic syndromes: Huntington's Chorea
- Alcohol-related: Wernicke's or Korsakoffs
- Drugs/toxin exposure: heavy metals, pesticides
- White matter diseases: MS
- Mass effects: tumors, NPH
- Depression and other psychological conditions
- Infections that cross the blood-brain barrier: C-J, HIV/AIDS, Lyme?
- Posterior Cortical Atrophy
- Progressive Supranuclear Palsy
- Or, could be a mixture of two or more types

The GEMS...

Sapphires: True Blue – Healthy Brain
Diamonds: Routines & Routines Rule - Clear/Sharp
Emeralds: Green/On the Go with Purpose – Naturally Flawed
Ambers: Caught In a moment of time – Caution Required
Rubies: Deep & Strong – Others stop seeing what is possible
Pearls: Hidden in a Shell – Beautiful Moments to Behold
FOUR TRUTHS ABOUT ALL DEMENTIAS:
1. At least two parts of your brain are dying
2. Nothing stops or cure it
3. It keeps progressing and changing
4. It is terminal

Stakeholders - Us
Care Partner and Others Around
- History – our background
- Awareness
- Knowledge
- Skills
- Competence
- Relationships
- Agenda(s)

The Person
- Past and Present
  - Life story
  - Early history
  - Personality traits
  - Preferences – how/when
  - Way values
  - Hobbies and interests
  - Likes and dislikes
  - Motives
  - Notable positive changes
  - Notable negative changes

Stakeholders - Us
- Us
- Care Partner and Others Around
  - History – our background
  - Awareness
  - Knowledge
  - Skills
  - Competence
  - Relationships
  - Agenda(s)
Us! People and Caregivers:

Should not:
- Argue
- Make up stuff not true
- Ignore behavior problems
- Try a possible solution only once
- Give up
- Let them do whatever they want
- Force them to do what you want

Remember who has healthy brain!
We have to control us; we can change
Recognize people with dementia are doing the best they can!

Ways to support as Caregivers
PAC SKILLS!!!

1. **PPA® & VVT**
   - Positive Personal Connections

2. **HuH®**

3. **Positive Action Starters (PAS)**

The Environment

Explore the Four Fs
- Friendly
- Functional
- Familiar
- Forgiving

Explore the Four Ss
- Space (intimate, personal, public)
- Sensations (see, hear, feel, smell, taste)
- Surface to Surface Contact (clothing on body, water on skin)
- Social (people, activity, role, expectations)
Environment: 4 F’s & 4 S’s

4 F’s: Friendly, Familiar, Functional, Forgiving
- What helps? What hurts?
- We control whether it is supportive
- Physical (sensory experience)
- People or how to engage socially
- Programming: to support what they like and what they need

4 S’s: Surface, Social, Sensations, Space
- Surface: Sit-stand-lie down-work
- Social: People-activities-role-expectations
- Sensations: See-hear-feel-smell-taste
- Space: Intimate-personal-public

Environment: 4 Fs

1. Friendly
2. Familiar
3. Functional
4. Forgiving

- What helps? What hurts?
- We control whether it is supportive
- Physical (sensory experience)
- People or how to engage socially
- Programming: to support what they like and what they need

Environment: 4 S’s

1. Surface
   - Sit-stand-lie down-work
2. Social
   - People-activities-role-expectations
3. Sensations
   - See-hear-feel-smell-taste
4. Space
   - Intimate-personal-public
Time

Time Awareness
- Where in life
- Time of day
- Passage of time

Balance in Four Categories
- Productive: Gives value
- Leisure: Fun-playful
- Wellness and self care
- Restorative calm – recharge

Wait Time vs Engagement in Life Time

Brain Changes
- Dementia
- Awareness of changes?
- Delirium? Depression or Anxiety?
- Gait changes
- Challenges abilities
- Variability
- Urine and duration

Structure of the Day
- Daily routines and programming
- Second piece we can control
- Filling the day with valued engagement
- Gem level programming

Types of Meaningful Activities
1. Productive: give value and purpose
2. Leisure: have fun, interact
4. Restorative: re-energize and restore spirit

Six Pieces of the Puzzle
- Life is challenging for a person living with dementia (Part 2)
- Learning how to give the best care possible
- Staying focused and alert
- Using six categories to help improve care
How To Use a 6-Pieces Huddle-Up!

Huddle: to arrive at plan
1. Share information, pieces of the puzzle
2. Figure out the problem (unmet need)
3. Develop a plan together
4. Negotiate who will implement what and how
5. Value and support each other, each role
6. Follow through and try out team’s plan
7. Obtain feedback: what worked and what didn’t?

Let’s see Dixie AFTER the Huddle up!

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