Living with Dementia: Shining a Light on Behaviors

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This 1.5 hour experiential learning session will immerse attendees into the world of an elder living with dementia. The program will “spotlight” behaviors that are often exhibited and will “shine a light” on the origin. Attendees will be provided with tools and strategies that can be utilized to successfully manage behaviors. The program includes demonstrations, role plays, open discussion and hands on learning with the various tools and strategies that can be used to effectively prevent and/or de-escalate behaviors.
At the completion of the program the participant will be able to:

✓ Recognize behavioral responses as a form of communication utilized by a person with dementia.

✓ Identify the root cause for behavioral responses.

✓ Utilize 3 strategies to prevent and/or de-escalate a behavioral response.
Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer's is the most common type of dementia.
Overview of Dementia

**QUICK FACTS**

1. It's the only cause of death in the top 10 in America that cannot be prevented, cured or slowed.
2. Almost two thirds of Americans with Alzheimer's disease are women.
3. 1 in 3 seniors dies with Alzheimer's or another dementia.
5. Only 45% of people with Alzheimer's disease or their caregivers report being told of their diagnosis.
6. More than 90% of people with the four most common types of cancer have been told of their diagnosis.
7. By 2050, these costs could rise as high as $1.1 trillion.
8. In 2015, Alzheimer's and other dementias will cost the nation $225 billion.
✓ Every 67 seconds someone in the United States develops Alzheimer’s Disease

✓ The number of people living with dementia worldwide is currently estimated at 47.5 million

✓ The number of cases of dementia are estimated to more than triple by 2050
Myth 1:
Memory loss is a natural part of aging.

Myth 2:
Alzheimer’s disease is not fatal.

Myth 3:
Only older people can get Alzheimer's.

Myth 4:
Drinking out of aluminum cans or cooking in aluminum pots and pans can lead to Alzheimer’s disease.
Myth 5:
Aspartame causes memory loss.

Myth 6:
Flu shots increase risk of Alzheimer’s disease.

Myth 7:
Silver dental fillings increase risk of Alzheimer's disease.

Myth 8:
There are treatments available to stop the progression of Alzheimer's disease.
4 Million in the United States Suffer from Dementia

60 Different Types

Two Most Common are Alzheimer Disease and Vascular Dementia
Alzheimer’s Disease – 60-80%

Early Symptoms: Difficulty remembering recent conversations, names or events

Later Symptoms: Impaired communication, poor judgment, disorientation, confusion, behavior changes and difficulty speaking, swallowing and walking.

Brain Changes:

- **Plaques** - deposits of the protein fragment beta-amyloid
- **Tangles** - twisted strands of the protein tau (tangles)
- **Nerve cell damage and death** in the brain
Vascular Dementia

Occurs because of brain injuries such as microscopic bleeding and blood vessel blockage.

**Symptoms:**

- Impaired judgment or ability to make decisions, plan or organize.

- The location, number and size of the brain injury determines how the individual's thinking and physical functioning are affected.

**Brain Changes:** Brain imaging can often detect blood vessel problems.
Symptoms:

✓ Memory loss and thinking problems common in Alzheimer's
  - HOWEVER -
✓ More likely to have sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.

Brain Changes: Lewy bodies are abnormal aggregations (or clumps) of the protein alpha-synuclein..
✓ More than one type of dementia occur simultaneously in the brain.

✓ Mixed dementia is more common than previously thought.

**Brain changes:** Characterized by the hallmark abnormalities of more than one type of dementia most commonly, Alzheimer's and vascular dementia, but also other types, such as dementia with Lewy bodies.
Frontotemporal Dementia

Includes dementias such as:

- Behavioral Variant FTD (bvFTD)
- Primary Progressive Aphasia

People with FTD generally develop symptoms at a younger age (at about age 60) and survive for fewer years than those with Alzheimer's.

**Symptoms:** Changes in personality and behavior and difficulty with language.

**Brain Changes:** No distinguishing microscopic abnormality
Complexity of the Human Brain

- **Frontal lobe**: Executive functions, thinking, planning, organising and problem solving, emotions and behavioural control, personality.
- **Motor cortex**: Movement.
- **Sensory cortex**: Sensations.
- **Parietal lobe**: Perception, making sense of the world, arithmetic, spelling.
- **Occipital lobe**: Vision.
- **Temporal lobe**: Memory, understanding, language.
✓ 100 Billion Nerve Cells (Neurons)

✓ Branches that connect to more than 100 trillion points

✓ These signals form the basis of our memories, thoughts, feelings
✓ Nerve cells connect to each other at synapses

✓ Signals (thoughts and feelings) move from cell to cell by an electrical charge
The brain tissue of individuals with Alzheimer’s Disease have fewer nerve cells and synapses than a healthy brain.

**Plaques** and **Tangles** interfere with neurotransmission.
✓ Nerve cell death

✓ Tissue Loss

✓ Over time the brain shrinks, affecting nearly all of its functions
✓ Progressing varies
✓ Average is 8 years
✓ Some may survive up to 20 years
✓ Learning
✓ Memory
✓ Thinking
✓ Planning
Mild Alzheimer’s Disease

- Problems with memory
- May get confused
- Difficulty handling money
- Difficulty organizing thoughts
- Difficulty expressing themselves
- Difficulty understanding speech
Severe Alzheimer’s Disease

✓ Loss of ability to communicate

✓ Loss of ability to recognize family and loved ones

✓ Loss of ability to Care for oneself
Write on the 3x5 card a precious memory

Write on a 3x5 card one of your most prized abilities

Write on a 3x5 card something or someone that you treasure
Each Person with Dementia will Present in their Own Unique Way

✓ No 2 people have the same personality
✓ No 2 people have the same memories
✓ No 2 people have had the exact same life experiences

We MUST know the PERSON behind the dementia
✓ Self Reflection
✓ Get to know Alice
✓ Root Causes
✓ IDT’s Role
✓ PACE Center
✓ Mercy LIFE’s Approach
✓ Remember the Caregivers
✓ Called on in class, and didn’t know the answer?
✓ Realized you were lost in a new city?
✓ Couldn’t remember someone’s name?
✓ Can’t remember meeting someone before?
✓ Couldn’t find a bathroom?
✓ Around people who speak a different language?
✓ Found out it was Thursday, not Wednesday?
Based on Still Alice (2007) by Lisa Genova

- What are Alice’s symptoms?
- What are her behaviors?
- What affect does the disease have on Alice?
- What affect does the disease have on her family?
- Who is Alice?
I am not suffering. I am struggling. Struggling to be part of things, to stay connected to who I was once.”

“I used to be someone who knew a lot. No one asks for my opinion or advice anymore. I miss that. I used to be curious and independent and confident. I miss being sure of things.”
Alice says…

- “There's no peace in being unsure of everything all the time.”

- “I miss doing everything easily. I miss being a part of what's happening. I miss feeling wanted. I miss my life and my family.”
✓ You always had to eat food without flavor?
✓ Someone was insisting you trust a stranger?
✓ Someone was trying to convince you that a stranger was your son, daughter, or spouse?
✓ You had to sleep in a strange house?
✓ Or, sleep next to a stranger?
✓ Someone was trying to take your clothes off?

Although we want dementia to be like The Notebook, dementia may be more like Momento...
<table>
<thead>
<tr>
<th>Emotion</th>
<th>Example Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Embarrassed</td>
<td>Crying</td>
</tr>
<tr>
<td>Scared</td>
<td>Sleep disturbance, rocking</td>
</tr>
<tr>
<td>Confused</td>
<td>Distracted</td>
</tr>
<tr>
<td>Panic</td>
<td>Screaming</td>
</tr>
<tr>
<td>Paranoid</td>
<td>Avoiding, hiding</td>
</tr>
<tr>
<td>Angry</td>
<td>Hitting</td>
</tr>
<tr>
<td>Disoriented</td>
<td>Wandering</td>
</tr>
</tbody>
</table>
✓ Unmet Needs
  • Bathroom, hot/cold, hungry, tired
✓ Medical Reasons
  • Medication, infection
✓ Co-morbid issue
  • Depression, auditory/visual disturbance
✓ “Moment of clarity”
  • Recognizing something is wrong can be unsettling
- Difficulty with tasks
- Unfamiliar surroundings
- Loud noises, frantic environment
- Inability to communicate
- May create behavior problems
- Physical discomfort
IDT’s Role

- Be a sleuth!
- In-depth Assessments/Reassessments!
  - What was the participant like before dementia?
  - What did the participant like to do in the past?
  - What kind of jobs did they do or enjoy?
  - Who did they enjoy spending time with?
  - What was the happiest time of their life?
  - What was the most difficult time of their life?
✓ AODA or psych history affects brain function
  • Substance, method, frequency, duration, treatment, abstinence
✓ Implement use of Industry Standard evaluations (MMSE)
How PACE center can help

✓ Environment
  • Quiet room
  • Nostalgia groups (music, historic event, stories)
  • Meaningful activities (cleaning, caring, helping)

✓ Staff education
  • Body language (i.e. crossed arms)
  • Verbal communication (stay with me vs. don’t go there)
  • Root causes
    o pain, bathroom, overwhelmed, confused

✓ Participant education
  • Buddy system
  • Separate activities
- Can still do some ADLs (although slowly)
- Can turn pages in a magazine or book
- Can remember songs or popular dances

Social
- May still be flirtatious or courteous
- Can fold calendars, menus, clothes
- Can clean dining room tables
- Can care for animals or baby dolls
- Has a sense of humor
- Is aware of surroundings, sometimes has an interesting perspective on what is happening around them!
Mercy LIFE of Philadelphia and Delaware County

- Current census of 650+
- Five diverse locations
  - Hancock: 1/3 Spanish speaking
  - Valley View: Deaf and blind
  - Assisi House: Sisters of St. Francis
  - Sharon Hill & Broad St: Changing population
- Dr. Earl Goldberg’s Ed.D., APRN, BC
- In-services – Psychiatric Boot Camp
Hancock: 1/3 Spanish speaking
  • Spanish Bible study, salsa music, telenovelas

Valley View: Deaf and blind
  • Photo reminiscing, cloud gazing, feed the fish

Assisi House: Sisters of St. Francis
  • Coupon cutting, prison pen pals

Sharon Hill & Broad St: Changing population
  • Snoezelen, pet therapy, “Name that Tune”
Don’t the Forget the Caregivers

- Promote patience
  - Trial and error
  - Remember the toddler years
  - Reduce/Normalize shame, anger, guilt
Get creative! There is always an alternative!

- Create lists of distractions, favorites, help
- Have a Plan B
  - Safe Return Program (1.888.572.8566)
  - Respite
- Stuck? Ask IDT or colleagues for suggestions!

Promote accessing support groups

- Identify supportive options (extra homecare, transportation voucher, informal supports)
➢ How would you like to be treated if you had dementia?
  • With love
  • With patience
  • With meaning