Understanding the Dementia Experience

Objectives:

- Demonstrate the impact the symptoms of dementia have on a patient's abilities through a simulation of empathy and sensitivity training.
- Demonstrate techniques to communicate with individuals with dementia.
- Demonstrate responsibility in providing person-centered care to avoid stereotyping and discrimination.

Impact of Symptoms:
Below are common, well-recognized symptoms of dementia:

- Difficulty with
  - Visual-spatial relations
  - Reasoning and abstract thinking
  - Language and ability to communicate
- Changes in
  - Executive functioning
  - Memory
  - Concentration
- Others: _________________________________________________________________________

These symptoms affect the interactions of people with dementia by:
______________________________________________________________________________________________
______________________________________________________________________________________________

Physical challenges associated with dementia include:

- Visual perception difficulties
- Difficulty with sensory inputs
  - “Agnosia”
- Diminished coordination
- Limited ability to complete motor tasks
  - “Apraxia”

These symptoms affect the interactions of people with dementia by:
______________________________________________________________________________________________
______________________________________________________________________________________________

We can address these challenges by:
______________________________________________________________________________________________
______________________________________________________________________________________________
______________________________________________________________________________________________
______________________________________________________________________________________________
Communication challenges associated with dementia include:

- Loss of memory
  - “Amnesia”
    - Word-finding difficulty
    - Repetition
- Inability to communicate
  - “Aphasia”
    - Loss of ability to speak in clear sentences
    - Loss of ability to understand
    - Unable to use words
- Revert to native language

These symptoms affect the interactions of people with dementia by:

______________________________________________________________________________________________
______________________________________________________________________________________________

We can address these challenges by:

______________________________________________________________________________________________
______________________________________________________________________________________________
______________________________________________________________________________________________

Communication Techniques

Verbal Communication

- Establish a respectful relationship (use preferred name and adult language)
- Be clear in your language (avoid slang and pronouns)
- Give simple directions, one step at a time
- Speak slowly and clearly
- Offer multiple cues
- ___________________________
- ___________________________

Non Verbal Communication

- Approach from front, slowly
- Match individual’s eye level
- Wait for a response
- Be mindful for your body language and facial expressions
- ___________________________
- ___________________________

Common Emotions Associated with Dementia

- Loss
- Isolation/loneliness
- Sadness
- Confusion
- Worry/anxiety
- Frustration
- Fear
- Paranoia
- Anger
- Embarrassment

Dementia is a subjective experience!
Person-centered Care

- Reframing our perceptions
  - Ability vs. Disability
  - Person vs. Patient
  - His/Her reality vs. Our reality
- Reframing our programming
  - Routine vs. Rigidity
  - Adaptability vs. Inflexibility
  - Appropriate vs. Personalized

We can develop Person-centered Care Programs by:

______________________________________________________________________________________________
______________________________________________________________________________________________
______________________________________________________________________________________________
______________________________________________________________________________________________

Remember to PAUSE:

Provide                                      ________________
Assess                                       ________________
Understand                                   ________________
Strengthen and Support                        ________________
Empathize                                    ________________

Contact Information:
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Language Boards:
Boards containing phrases from another language phonetically translated into English. The boards are designed for staff to learn the PWD’s native language. Allowing PWDs to hear phrases in their native language removes the issue of poor auditory comprehension of English.

FOCUSED Program for Caregivers (Ripich, Ziol & Lee, 1998):
Training program consisting of 7 strategies to compensate for communication challenges.
The Seven Strategies:
• Face-to-face to attract attention
• Orientation to topic of conversation
• Continuity or maintenance of the topic
• Unsticking for overcoming communication blocks
• Structured in how questions are formed
• Exchange ideas, needs, and feelings during conversation
• Direct in the types of verbal messages

Pictorial Memory Aids:
Memory aids that consist of pictures accompanied by short phrases or sentences. This method is often used to relay factual information and help compensate for episodic memory loss. They can be used as room identifiers, content descriptions, and general conversation starters.

Validation Therapy:
Based on Carl Roger’s client-centered therapy and the Feil Method, this strategy focuses on stepping into the reality of the PWD. Instead of correcting him or her, the caregiver validates the PWD’s feelings and redirects the behavior or conversation.

Written Cues:
Provide written cues to decrease repetition. Cues can be on sticky notes, index cards, or dry erase boards. Also, daily or weekly calendars assist with activity recall.

Shorten Messages:
Shortening phrases lessens the load of communication demands on the PWD and helps caregivers compensate for episodic memory.

Reduce “Opportunity to Communicate” Barriers:
To remove the barrier of “opportunity to communicate,” arrange furniture to invite conversation and provide conversational partners for each person. Also, provide group activities to eliminate the problem of what to talk about.
Supplement 2:
Tips for Environmental Modifications
Adapted from *Interventions for Alzheimer’s Disease*, R. Tappen. 1997 Baltimore, MD, Health Professions Press

Goals:
1. Treatment (therapeutic effect)
2. Dignity and Privacy
3. Normalization
4. Allowance for Individual Differences
5. Tolerable Stimulation
6. Facilitation of Function
7. Safety

Specific Modifications:

- **Exit Control:** Provide the PWD with a safe and secure environment without compromising his/her dignity.
  - Secure (and sometimes concealed) entrances and exits
  - Identification of PWDs
  - Secured outdoor areas
  - Automatic locking areas
  - Electronic security systems

- **Spaces for wandering and pacing:** Provide the PWD with a safe environment that encourages exploration.
  - Secure outdoor spaces
  - Open indoor spaces (hallways, main activity floors)

- **Places to Gather:** Create a gathering area that is warm, comfortable, pleasant and conducive to social interaction (consider furniture arrangements)

- **Places to Get Away:** Provide PWD with space to retreat from the crowd outside of their bedroom, such as relaxation rooms and libraries.

- **Natural Areas:** Provide PWD access to the relaxing and therapeutic sounds of nature (consider gardens, courtyards, and patios)

- **Sensory Input:** Modify sensory inputs to maximize the functioning of the PWD.
  - **Visual Input:** Use representative symbols for objectives instead of color coding, choose colors with relaxing effects, limit use of printed wallpaper, and limit access to mirrors (if applicable).
  - **Olfactory Input:** Minimize chemical smells and maximize comforting smells, like garden and kitchen scents.
  - **Aural Inputs:** Minimize multiple loud sounds and maximize soft, muted tones; encourage quiet times for individuals who are agitated.

- **Individual Assessment:** Take into consideration the individual when making environmental modifications.
An Alzheimer’s Disease Bill of Rights

Every person diagnosed with Alzheimer’s disease or a related disorder deserves the following rights:

- To be informed of one’s diagnosis
- To have appropriate, ongoing medical care
- To be productive in work and play for as long as possible
- To be treated like an adult, not like a child
- To have expressed feelings taken seriously
- To be free from psychotropic medications, if possible
- To live in a safe, structured, and predictable environment
- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact including hugging, caressing, and hand-holding
- To be with individuals who know one’s life story, including cultural and religious traditions
- To be cared for by individuals who are well trained in dementia care

From The Best Friends Approach to Alzheimer’s Care, V. Bell & D. Troxel, 1997, Baltimore, MD, Health Professions Press

Fundamentals of Dementia Interventions

1. The person with Alzheimer’s disease or a related dementia is still an adult and wishes to be treated as one.
2. Some capacity to learn continues until the latest stages of [dementia].
3. People with dementia continue to feel and respond to affection, joy, anger, sadness, and fear.
4. Awareness of the environment and of the people in it continues into the late stages.
5. A sense of self remains.

Adapted from Interventions for Alzheimer’s Disease, R. Tappen. 1997 Baltimore, MD, Health Professions Press

Assessment Factors for Dementia Interventions (The Who, What, and Where)

- Person (Who)
  - History
  - Medical and physical status
  - Emotional status
  - Cognitive status
    - Sensory functions
    - Perception and comprehension
    - Executive functions
    - Expressive functions
    - Motoric functions
  - Preferences and interests

- Task (What)
  - Emotional Appeal
  - Physical Demands
  - Cognitive Complexity
  - Social Context

- Environment (Where)
  - Physical
  - Social
  - Emotional
  - Cognitive