Objectives:

Participants in this education program will be able to:

1. Describe the communication challenges that are associated with the brain changes in various forms of dementia.

2. Translate various non-verbal ways people with dementia may communicate to express their physical, psychological and social needs.

3. Implement changes in your verbal and non-verbal approach while working as a care partner for people with dementia.
What is communication?
https://www.skillsyouneed.com/ips/what-is-communication.html

Dementia Types

Cluster of symptoms that may include...
- Decline in memory/recall
- Loss of advanced thinking skills
- Disorientation to oneself, time, place
- Impaired judgment
- Impaired problem solving
- Severe enough to limit their everyday activities

BUT:
- Different types represent different brain changes
- All people are unique

http://neurowiki2014.wikidot.com/group:dementia
Overview (Klimova and Kuka, 2016)

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Key Speech/Language Impairments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Dementia</td>
<td>Finding the right word for objects, naming the objects, word comprehension, voice volume</td>
</tr>
<tr>
<td>Parkinson’s Disease Dementia</td>
<td>Non-articulated speech, loss of verbal fluency, non-grammatical sentences, slow speech, voice volume</td>
</tr>
<tr>
<td>Dementia with Lewy Bodies</td>
<td>Language disorders include both the symptoms of AD and PDD</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>Finding the right word for objects, naming the objects, word comprehension, incomprehensible speech, decreased complexity</td>
</tr>
<tr>
<td>FTD- Nonfluent/Agrammatic</td>
<td>Slow and hesitant speech, grammatical mistakes, worsened understanding of complex sentences, finding the right word for objects, loss of literacy skills such as reading and writing</td>
</tr>
<tr>
<td>FTD- Semantic</td>
<td>Finding the right word for objects, naming the objects, word comprehension, lack of vocabulary, loss of literacy skills</td>
</tr>
</tbody>
</table>

Well-Being

Suggested Ordering of Well-Being Domains

The Eden Alternative Domains of Well-being™

POWER GA, 2014
While communication may be impacted—what is preserved?

(Gowdin and Poland, 2015)

Preserved continuity in sense of:
- Self
- Moral awareness
- Diversity of emotional reactions to living with dementia

Methods to improve self for PWD
- Increase sense of belonging
- Experiencing autonomy
- Experiencing engagement
- Promoting imagining
- Promoting sense of self

Why do we think that someone with dementia can’t communicate when they aren’t using words?
“...the urge to communicate is retained even if words are not (Ellis and Astell)

- Mehrabian 1971 first quantified that generally communication is generally split between 3 channels.
- Does not apply to all circumstances- however when information is incongruent- that larger percentage areas are more often the accurate determinant.
- Other key factors: (Thompson 2011)
  - Context
  - Clusters
  - Congruent
Alzheimer’s Disease impacts the limbic system—associated with memory and emotion

If words aren’t making sense—listen to the tone

<table>
<thead>
<tr>
<th>Is it anxious?</th>
<th>Does it show despair?</th>
<th>Are they afraid?</th>
<th>Are they excited?</th>
</tr>
</thead>
</table>

Behavioral and Psychological Symptoms of Dementia (BPSD) versus Behavioral Expressions

Medical Model vs. Biopsychosocial Model

Behavioral expression - Looks at attempts to maximize communication and well-being.

Focus on what the person with dementia is trying to tell you.

BPSD “labels” the problem on the individual and identifies it as something to be managed.
Communication of Needs

- Pain
- Hunger/Thirst
- Fatigue
- Need to use the bathroom
- Boredom
- Overstimulation
- Feeling lost/insecure
- Aggression

Body Language: Pain PACSLAC II (Hadjistravropoulos, 2010)

**Facial Expressions**
1. Grimacing
2. Tighter face
3. Pain expression
4. Incresed eye movement
5. Wincing
6. Opening mouth
7. Crossing forehead
8. Lowered eyebrows or frowning
9. Raised cheeks, narrowing of the eyes or squinting
10. Wrinkled nose and raised upper lip
11. Eyes closing

**Verbalizations and Vocalizations**
12. Crying
13. A specific sound for pain (e.g., ‘ow’, ‘ouch’)
14. Moaning and groaning
15. Grunting
16. Gasping or breathing loudly

**Body Movements**
17. Flinching or pulling away
18. Thrashing
19. Refusing to move
20. Moving slow
21. Guarding sore area
22. Rubbing or holding sore area
23. Limping
24. Clenched fist
25. Going into foetal position
26. Stiff or rigid
27. Shaking or trembling

**Mental Status Changes**
31. Are there mental status changes that are due to pain and are not explained by another condition (e.g., delirium due to medication, etc.?)

**Changes in Interpersonal Interactions**
28. Not wanting to be touched
29. Not allowing people near

**Changes in Activity Patterns or Routines**
30. Decreased activity
Pain for People With Dementia

Systematic Review of pain in people with dementia, estimates 46-56% of people with dementia have pain (van Kooten, 2016)

Pain is under-recognized and under-treated

- Systematic Review fund nursing home residents with dementia are given less pain medication despite similar number of conditions. (Tan, 2015)
- Systematic Review of people with hip and pelvic fracture and dementia were given 50% less pain medication dementia than cognitively intact older adults (Moschinski, 2017)
- Systematic Review found people with dementia had worse oral health but were recognized as having oral pain less than cognitively intact older adults (Delwel, 2017)
- Cohen Mansfield (2005) found 60% of people with dementia were identified as likely having oral pain by dentist assessment

Pain/Alzheimer’s Dementia (Achtreberg, 2013)

Believed that behavioral responses to pain are more significant in early/moderate dementia

- Hyperalgesia- response to chronic pain with increased sensitivity to painful stimuli
- Allodynia- painful response to nonpainful stimuli
Pain impact on behavioral expressions

Systematic Review and Meta-analysis (van Dalen-Kok, 2015) found some association between pain and:

- Agitation/aggression
- Anxiety
- Hallucinations and delusions
- Disruptive behavior
- Wandering
- Challenges with personal care

Question: how many people are being treated for anxiety or psychosis when they are really having pain?
Body Language: Hunger/Thirst

- Putting things towards their mouth
- Holding their stomach
- Eating inappropriate things
- Taking other peoples food or drink
- Repeated swallowing
- Searching for things

**hangry**

*(hang-gree) adj.*
a state of anger caused by lack of food; hunger causing a negative change in emotional state.

Body Language: Fatigue

- Blank gaze
- Turning away from activity
- Nodding off
- Rubbing eyes
- Irritable
- Searching for a bed

https://www.nia.nih.gov/health/fatigue-older-adults
Need For Bathroom

- Touching in groin area
- Pulling on pants
- Undressing
- Searching for room/bathroom
- Anxiety

BOREDOM
- Searching in or for things
- Taking other peoples things
- Bickering
- Over-eating
- Following staff or carepartner
- Self-stimulation via repeated movements

OVERSTIMULATION
- Leaving an area of noise
- Hands over ears
- Closing eyes
- Anxiety
- Crying
Feeling lost or insecure...

- Searching for people or items
- Distress
- Crying
- Suspicious
- Anxious

Body Language: Aggressive

- Jaw thrust
- Nostril flaring
- Chest puff
- Pupil dilation
- Body blading
- Body tightening
- Ocular tension
- Rattling
Professional Practice Challenges

Task Specificity/ Task Talk
Elderspeak
Ethical Consideration
Maintaining Personhood

“Task Talk”
Caregivers maintained control over the content and dynamics of care conversation by initiating 75% of all interactions, and guiding the direction of the conversation 81% of the time to the task at hand.

(Iwasiw and Olson 1995)
“Elderspeak” (Williams K, et al 2009)

What is Elderspeak?
- Simplistic vocabulary and grammar
- Shortened sentences*
- Slowed speech
- Elevated pitch and volume
- Inappropriately intimate terms of endearment
- Collective ‘We/Our”
- Tag questions- “you want to get up now, don’t you?”

Older adults who listened to directions for completing a task (spoken using elderspeak) reported that the communication was patronizing, demeaning, and made comprehending the instructions difficult.

Observation of taped interactions found that there was a greater likelihood of resistance to care after “elderspeak” episodes in residential care facilities.

Staff was more likely to use “elderspeak” when residents were “neutral” (coded as neither cooperative or resistant to care)

http://www.movingsolutions.com/2013/07/09/elderspeak-babtalk-directed-at-older-adults/

Why is “Elderspeak” not helpful?
(Williams K, et al 2009)
You live here now

Your Mother is Dead

Your children aren’t in school any more

Truth, Untruth, Lies

Truth- shared reality and accurate information

Untruth- utterances, in an attempts to match the other persons reality, convey less than the whole truth

 Lies- misinformation that is not based on the other persons reality or on their well-being
Range of Responses  (Kirtley and Williamson, 2016)

- **Whole truth telling**
  - Show Nora pictures of funeral
  - Provide support

- **Looking for alternative meaning**
  - What is Nora seeking?
  - Love, physical affection, comfort

- **Distraction**
  - Nora likes the garden- visit
  - Nora enjoys music

- **Going along with**
  - Nora asks if John is working, you note it is during normal working hours and indicate she is likely correct

- **Untruth/Lying**
  - You offer without prompt that John must be at another location
Four Principles of Effective Communication

1. Cognitively impaired persons have special communication needs resulting from their emotional dependency and their inability to make concessions and accommodations.

2. The responsibility for understanding and being understood lies with the caregiver.

3. Our most important task is to establish and nurture a partnership of mutual trust and respect.

4. The person we are working with has a real and persistent communication disability. Although we cannot make the disability go away, we can employ effective strategies to help overcome specific problems.

When one person has dementia, communication is no longer an equal balance.
We do: Too much, too fast

We talk too much
  ◦ Use short, single idea sentences
We talk too fast
We talk with attitude and control
  ◦ “you need to sit down”
Try to rush
Ask complicated questions
  ◦ Focus on task and not person
  ◦ Instead focus on the person and not just the task!

Physical Approach

Reduce or minimize environmental noise
Consistent positive physical approach
  ◦ Pause at edge of their space
  ◦ Gesture and greet by name
  ◦ Make eye contact and offer your hand
  ◦ Approach slowly and stay in sight
  ◦ Shake hands
  ◦ Move to eye level and give them space (move to the side)
  ◦ Wait for acknowledgement

https://woodhaven-retirement.com/opening-doors-communication/
Smile!

http://successify.net/2014/04/10/wisdom-happiness-92-years-old/

Verbal

One staff speaks at a time.
Use yes-no rather than open-ended questions.
Speak at an adult level. Avoid “elderspeak”.
Allow time to process and respond. (10-30 seconds)
Repeat or paraphrase if necessary.
Do not correct the person.
Do not argue.
Do not pressure for response.
Habilitation Therapy (Raia 2011)

Goal:
- To create a positive emotion and sustain that throughout the day via one (or more) domains
- To reframe the approach for care of individuals with progressive debilitating disease to delivering care in the “here and now”.
- Creating a sense of purpose
- Recognizing the emotional message in communication even if not the specific words

Domain of Habilitation

Resource: http://www.healthcarefornewengland.org/initiatives/nhquality/nh-resources/
Implicit Memory retains longer than explicit memory.

Questioning
- Asking about recent events that they are unlikely to remember causes anxiety, agitation or anger

Repeated questions from PWD
- Mirror question back - rather than explicit memory (what time did I tell you), use implicit memory
- Example - scheduling a follow up time for tomorrow, person ask repeatedly, respond on next question with “what time do you think we should meet”. Likely to be able to say the answer.
- Less pressure on response
- Face saving with prompts

Avoid asking questions they are unlikely to know the answer to

Big challenge for families who want the PWD to remember
- We are unlike to “fix” them
- We can reminisce to discuss shared history
- PWD retain emotional memory
Pearls: When someone repeats the same phrase

Caregivers often feel marginalized when the PWD repeats the same question or phrase.
- Feel not heard or listened too
- Feel the PWD is being deliberately difficult

Neither is likely accurate but create tension in the relationship and interactions.

Recognize that this is not deliberate- and that this is a direct result of the disease.

Pearls: You get to change your answer until you find the best fit

When someone is starting to get distressed and you are trying to find the right answer. See their response... is it helpful or hurtful.

Example: Gentleman searching for “Betsy”
Conversational repair - when one or more parties in the conversation attempt to resolve misunderstandings or mishearing.

As dementia progresses, the sentence structure used may become more fragmented with long pauses and disjointed thoughts - the care partner will need to assume greater responsibility for conversational repair.

Alzheimer’s Association - Practice Recommendations for Person Centered Care
(Fazio 2018)

1. Know the person living with dementia
2. Recognize and accept the other person’s reality
3. Identify and support opportunities for meaningful engagement
4. Build and nurture authentic and caring relationships
5. Create and maintain supportive community for individuals, family and staff
6. Evaluate practice regularly and make appropriate changes
Questions? Thank You!

For more information please contact me:
Living Well With Dementia, LLC

[Link](http://www.livingwellwithdementiallc.com)

cciolek@livingwellwithdementiallc.com

302-753-9725
References: Communication skills for working with people with dementia

- Godwin B and Poland F (2015) Bedlam or bliss? Recognizing the emotional self-experience of people with moderate to advanced dementia in residential and nursing care. QUALITY IN AGEING AND OLDER ADULTS. 16(4)235-248
- Sabat S. (2018) Alzheimer’s Disease and Dementia; What everyone needs to know. Oxford University Press.

