"I'm a Real Person Too"
The Impact of Communication on
Behaviour for People with Dementia

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Illustrations by Don Bellamy
Introducing Don Bellamy

- “I’m a real person too.”
Outline

- What is communication?
- How does dementia affect communication?
- What does this mean for me as care provider?
- What do we do that may cause responsive behaviours?
- How can we reduce our contribution to responsive behaviours through communication?
What is communication?
First Communications

- What are our first communications?
- What do they mean?

Kit4na https://www.flickr.com/photos/kit4na/6241060744/
Function Of Communication

• Fundamental requirement for all human beings
• Essential for survival and growth and self-worth and belonging, identity
• Expression of needs
• Dignity
• Control

• Conveys meaning that goes beyond the spoken words
Communication is a Process

Like an ocean

• Active
• Continuous
• Flowing
• Changing

If you look at one bucket sample you don’t see the whole picture

If you look at a sentence word or gesture in isolation you do not get the whole message (– jacket)
Communication is a Transaction

Both individuals are affected by the other

Complex interaction of skills

- Listening
- Observing
- Speaking
- Questioning
- Analyzing
- Evaluating
Communication and Relationships

- A spoken sentence conveys much more than the information in the sentence – it is a reflection of the relationship.
- Communication changes based on who you are talking to and in what situation.
Consider the following paralinguistic features – what are your unique traits?

<table>
<thead>
<tr>
<th>Volume</th>
<th>Rate of speech</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tone of voice</td>
<td>Pitch</td>
</tr>
<tr>
<td>Hand gestures</td>
<td>Eye contact</td>
</tr>
<tr>
<td>Vocabulary</td>
<td>Body language</td>
</tr>
<tr>
<td>Emphasis</td>
<td>Conversational cues</td>
</tr>
<tr>
<td>Proxemics</td>
<td>(hmmm)</td>
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</tbody>
</table>
Let me introduce myself...

- Take a moment to introduce yourself to the person or people next to you
- Tell them your name, and a little bit about yourself then let them tell you about themselves
- Ask each other one question to find out more
- If you know the person beside you well, find someone new to meet as well
Reflect:

- What paralinguistic features do you use? What is your style?
- What did you sound like, look like?
- What were your partner’s features?
- This is normal communication
Non Verbal Communication

Communication is said to be 7% verbal, 93% non-verbal

- 38% tone
- 55% body language
Incongruence between verbal and non verbal
Non-Verbals and Dementia

With dementia, people live in the here and now

• May not remember the details
• May not be able to understand the details
• They know how they feel and they retain the emotions from an interaction
What happens with communication in dementia?
Dementia Deficits of Communication

Early Stages:

• Tip of the tongue feeling
• Takes longer to process – 30-60 seconds
• Difficulty staying on track
• Aphasia (word finding difficulty)
• Repeating
Dementia Deficits of Communication

Middle Stages

- Forget more complex words
- Neologisms
- Increased generalizations
- Greater reliance on social phrases
- Difficulty following instruction
- Less initiation of conversation
Dementia Deficits of Communication

Late Stage

- Single words
- Limited initiation
- Nonverbal sounds
- Communication as a whole is predominantly nonverbal
Other Communication Barriers

Hearing loss

• Loss of ability to hear higher pitches
• Substantial hearing loss not unusual

Vision loss

• Many visual cues are used in communication
• Conversational cueing
• Feedback
• Decoding

Dentures
Remember:

Lack of initiation/engagement of conversation does not imply a lack of desire for communication.

Ability to UNDERSTAND the spoken word long outlasts the ability to COMMUNICATE the spoken word.

Ability to understand and experience the emotions involved in communication long outlasts the ability to understand the spoken word.
Results of Impaired Communication

- Unmet needs
- Frustration
- Anxiety
- Decreased self esteem
- Increased social isolation
  - Interaction with individuals with dementia is often superficial and brief.
  - Not being understood increases isolation
Results of Impaired Communication

Responsive Behaviours

- Hostility
- Aggression
- Yelling
- Swearing
- Pushing
- Grabbing
- Refusing
What does this mean for me as care provider?
Telephone Game?

Telephone Game?

- With increasing deficits, communication ceases to be 50/50 and becomes more 80/20
What do we do that may CAUSE responsive behaviours?
What do we do?

How to we promote responsive behaviours?

• Task orientation/isolation
• Removing control
• Not engaging fully
• Not responding to the emotion/intended message
• Elderspeak
Task Orientation/Isolation

- Focusing on the task, not the person
- Only engaging with them when there is a task to be done
Removing Control

• The desire to have control over ourselves and our lives is fundamental to people of all ages
• We all want to feel as though we have influence over ourselves and our surroundings
• Feelings of helplessness and loss of control lead to reduced cooperation and acting out
• **This is not unique to dementia...**
Picture Day

Control.

A life-long need.
Not Engaging Fully

- Multi-tasking
- Being disconnected
- Generic responses
- Back to them
- Talking to others as though they are not there
Not Responding to the Emotion

- Focusing only on the words
- Looking at the bucket of water

Listening to reply rather than listening to understand
**Elderspeak**

- Demeaning Names – Sweetie, Honey
- Infantilizing speech
- High Pitched Voice
- Demeaning Non Verbal – pat on the head
- Baby Words – go potty
- Speaking loudly when not required
- Exaggerated Intonation
- Everything sounds like a question

**AVOID ELDERSPEAK**

- The Royal We
- App store?
Elderspeak

- Greatly increases the likelihood of uncooperative behaviour when doing tasks
- Demonstrates power imbalance and reinforces loss of control
- Demonstrates lack of respect for individual and who they are
- Increases depression and agitation
- May be interpreted as abusive

Even if dementia is so advanced that the words are not understood, the feelings associated are perceived and retained
“Hi Sweetie. It’s time for our exercise today. Let’s get ready to walk down the hall.”

Vs.

“Hi Mrs. Smith. It’s time for your exercise today. May I walk down the hall with you?”
Elderspeak

Effect on Person with Dementia:

- Feel incompetent
- Feel discouraged
- Feel disrespected
- Alters self perception
- Reinforces and imposes dependency
- Insulting
- Depression
- Withdrawal

Greatly increased likelihood of resistance to care
Herman, R & Williams, K. (2009). Elderspeak’s influence on resistiveness to care: focus on behavioural events. American Journal of Alzheimer’s Disease and Other Dementias 24(5) 417-423
Elderspeak

Effect on perception of care provider by third party and care recipient:

- Disrespectful
- Patronizing
- Unprofessional
- Angry
- Frustrated
- Dislikable
- Unintelligent
- Poor communicator
Strategies

How can we reduce our contribution to responsive behaviours through communication?
Empathic Curiosity

- A standpoint of trying to focus our attention on the perceptual experiences of another as they are experiencing them here and now
- More than empathy – empathic listening with maintaining a curious attitude toward nonverbal cues and behaviours

Remember: All communication has meaning
Strategies

MESSAGE

M – Maximize attention
E – Expression and body language
S – Simple
S – Support the conversation
A – Assist with visual aids
G – Get their message (empathic listening)
E – Encourage and engage in conversation
M – Maximize Attention

- Give cues before engaging them
- Identify yourself
- Use their name
- Eye level and eye contact
- Remove distractions – quiet environment
- One person talking at a time
- May use touch to aid concentration

Try it! – strike up a conversation with your neighbour
E – Expression and Body Language

- Stay calm and relaxed
- Do not multi-task if you can help it
- Smile – facial expressions
- Lean forward
- Eye contact
- Even tone – do not over emphasize tone of voice

Try it! – talk to your neighbour about the forecast
S – Simple

- Keep messages familiar and short – but not infantilizing
- One message at a time
- Clear choices (Elvis or the Beatles?)
- Fewer pronouns
- Do not test – avoid factual questions that rely on recent memory
- Present tense

Try it! – Tell your partner that it is lunch time and ask them what they would like to drink – consider pacing, spacing and clarity of choices.
S – Support the Conversation

- If interrupted, reintroduce the topic
- Provide more time to process
- Repeat and rephrase – maintain tone
- Repeat part of what you heard to encourage them
- Do not pressure
- Help with word finding
  - Find a balance between allowing time and causing distress

Try it! – Ask your partner about where they grew up – if they don’t reply, rephrase or repeat
A - Assist with Visual Aids

- Gestures or actions
- Objects or pictures
- Show options
**G – Get Their Message**

- Start with the attitude that all behaviour and communication has meaning
- Focus on *feelings*, not *facts*
- Look for micro behavioural cues
- Provide feedback – mmm hmm...
- Look at the big picture
  - Body language cues
  - Look for and respond to the emotion behind the message
  - What is the person’s history?
Try it

- What is your first impression/reaction if faced with these behaviours?
- What else might these behaviours mean? (3 ideas!) – what response might be required?

- Calling out for mother
- Pulling at your sweater
- Repeatedly wandering into the kitchen
- Refusing to sit at a meal
- A loud sigh
E – Encourage and Engage in Conversation

- Interesting and familiar topics
- Do not test them – yes and no - statements
- Avoid reality orientation
- Alternative techniques to communicate – writing, pictogram, gesturing
- Use positives rather than negatives when possible
- Do not argue with them
Other Strategies

- Account for other communication barriers – hearing, vision – and use available aids
- Support client control and self esteem
- Do not be afraid to laugh
- Share what works
Humour Therapy

- A basic need throughout the life span

- Humour and play have many benefits
  - Cardiovascular
  - Respiratory
  - Immune
  - Pain
  - Stress relief
  - Diabetes
  - Connection
  - Distraction
  - Communication
  - Equality
  - Ability to try things without risk
  - Makes new connections

Strategies - Humour
Humour Therapy

- 2011 SMILE study Sydney Australia
- Cluster randomized controlled trial evaluating the effect of humour on depression, agitation, social engagement and quality of life of nursing home residents
- Involved 398 residents
- Involved humour therapy training for one staff and 9-12 visits by professional “elderclown”
Humour Therapy

- No significant outcome change in depression found
- Agitation outcome was a significant decrease
- Equivalent to two agitated behaviours decreasing from daily to once a week
- Similar outcome to risperidone – without the side effects
How Does Humour Stack up?

Humour
• Enhances connection
• Removes power barriers
• Is fully engaging
• Is an emotional message
• Is a normal part of communication

How to we promote responsive behaviours?
• Task orientation/isolation
• Removing control
• Not engaging fully
• Not responding to the emotion/intended message
• Elderspeak

— Freeman
OK but...

- I’m no “elderclown”
- There are downsides to humour
- I’m not funny

Everyone can use humour
5 Rights

Right Drug
- Right type of humour
- Avoid sarcasm, gallows humour
- Take cues from the other person - assess

Right Dose
- Could be just a smile

Right Route
- Where are you coming from?
- Laugh WITH not AT

Right Person
- Must know your audience
- Must be trust established

Right Time
- Never during crisis
Communication, Dementia and Frustration

- Communicating with someone with dementia can be frustrating
- Constant reminder of loss
- Fear
- So what if you slip? What if you find yourself not using your equality and respect voice?
  - Regroup and try again
  - Forgive yourself
  - Self care

What is communication?
Two Stars and a Wish

- Give yourself credit for your successes
- Two Stars to celebrate what went right
- A wish for something that didn’t

- All that you can do is take it one experience at a time. Be kind to yourself. Cherish the successes.
References


Manitoba Health Enhanced Orientation for Nurses new to Long Term Care Clinical Workshop 2: Manitoba Health

Young, T., Manthorp, C., Howells, D. & Tulla, E. (2011). Optimizing communication between medical professionals and people living with dementia *International Psychogeriatrics* 23(7), 1078-1085