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Engagement Elixir: Enhancing Communication Experiences for People Living with Memory Impairment

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Session Objectives

- Describe the impact of one-sided communication with those with memory impairment
- Create and use a set of questions designed to evoke stories and conversations from those with memory impairment
- Act as ambassador to train, empower and support others in using powerful questions to engage residents, family and community members through artful question asking

“Rather than trying to bring the person with dementia back to reality, why not try to enter their reality”

Bob DeMarco, AlzheimersReadingRoom.com



Ain't She Sweet, LLC





What is one-sided communication?

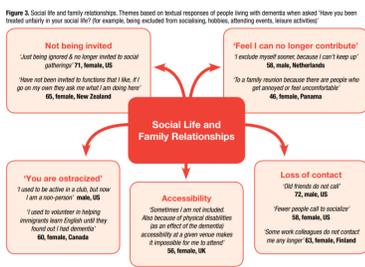
One sided communication occurs often unintentionally, when...

- ❖ Both people don't feel valued
- ❖ Both people don't feel included
- ❖ Both people are not equally engaged
- ❖ Both people cannot equally comprehend the content of the conversation
- ❖ Both people are not fully comfortable in the conversation



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The Impact of Isolation



"A recent global survey by Alzheimer's Disease International found that 38% of those living with dementia in high-income countries, including the U.S., report feeling avoided, ignored and ostracized in their social lives."
 -- Wall Street Journal, 2019

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Graphic from 2019 World Alzheimer's Report © Alzheimer's Disease International

The Health Risks of Loneliness

"Research has linked social isolation and loneliness to higher risks for a variety of physical and mental conditions: high blood pressure, heart disease, obesity, a weakened immune system, anxiety, depression, cognitive decline, Alzheimer's disease, and even death."
 -- NIH, 2019



- Social isolation is the **objective** physical separation from others (living or alone)
- Loneliness is the **subjective** feeling of being separated from others or a distressed feeling of being alone

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Adapted from: National Institute of Health, "Social isolation, loneliness in older people pose health risks", April 2019

How to handle someone shutting down

- DO give them a few minutes to sit in peace
- Do NOT keep asking them if they are ok
- DO ask them if there's something they'd like to talk about
- Do NOT try to use guilt or pressure to elicit communication
- DO look for objects around them that may stimulate conversations
- Do NOT pressure them to remember something you feel they should remember
- DO assure them it's ok if they are not up to talking and you will return another time



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Living with Dementia

Behaviour

- Over 85% of respondents living with dementia stated that their opinion had not been taken seriously
- Around 40% of the general public think doctors and nurses ignore people with dementia
- 67% of people living with dementia in Africa, and 63% in South East Asia, said their dementia symptoms were joked about by others
- Between 35% in high income countries and 57% in low-middle income countries reported being treated unfairly in dating and intimate relationships
- Around 30% of people in Europe are willing to have a person with dementia move in with them, rising to 62% in South East Asia and 71% in the Eastern Mediterranean region

"I call it the friendship divorce. I have lost a fair amount of people in my life that I at one time considered friends," wrote one respondent, while another said, "People tend to run when they learn you have dementia"
 -- Wall Street Journal, 2019



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Graphic from 2019 World Alzheimer's Report © Alzheimer's Disease International

The Power of Artful Questions

- Sincere questions show **Interest, Engagement and Concern**
- **Artful** questions are targeted to inspire conversation and comfort
- **Person Centered** questions are designed with the **other** person in mind
- The **Power** in these types of questions is the ability to create and **sustain** conversations, which **engage** people in all ranges of cognitive capacity

That's what you do for someone you love, you risk how you feel for what they want.



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Creating Customized Questions

Tips for successful communication

- Speak clearly and with a calm tone
- Slow down your pace, even more slowly than you feel comfortable with – pause between sentences giving people time to process
- Use simplified and short chunked out questions
- Focus on creating a conversation, not a cross-examination

"Don't talk about the person as if they are not there or talk to them as you would to a young child – be patient and have respect for them."

Try, "Were the French fries crispy" instead of, "how was your lunch".

Try, "What song would you like Margaret to sing?" or "Would you like to listen to Margaret sing Unforgettable?" instead of, "What do you remember about Margaret?"



Strategies to create custom questions

- Look for visual or auditory clues
- What is the person wearing?
- Are they clutching any close objects that seem important?
- What cues in the space around them indicate important people, hobbies or interests?
- Is there music/ television or other sounds, which seem to enhance or distract comfort?
- Consider questions, which are not time or memory bound
- Ask open ended questions, which do not require pressure to answer
- Have options to change topics if a topic seems to trigger or upset the other person



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Adapted from Alzheimer's Society, 2020

Practice Activity | Question Creation

Think about someone in your personal or professional life with Dementia who you'd like to increase the quality of engagement with.

What did it look like the last time communication was successful? Unsuccessful?

Is there a topic that seems to put this person at ease? Easily distress them? What have they responded best to? Worst to?

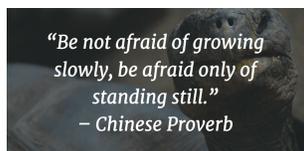
Create three questions designed to engage them in a comfortable conversation.



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How to Know when the Timing is Right

- ✓ Consider whether there is a time of day where the person is better able to communicate based on their preferences (AM or PM)
- ✓ Make the most of the good days a person has and try not to become discouraged during the bad ones
- ✓ Make sure you have their full attention by sitting closely and maintaining eye contact
- ✓ Look for cues to ensure you are not invading their personal space
- ✓ Find a place to talk with little to no interruptions, if possible
- ✓ Rephrase your questions, rather than repeat them so people do not think you're talking down to them
- ✓ Use nonverbal aids (photos, objects, food, etc.) to help reinforce the conversation
- ✓ If you feel frustrated or upset, take a quick break to ensure you can maintain your composure



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Adapted from Alzheimer's Society, 2020

Person Centered Story-Telling

"THERE IS NO GREATER AGONY THAN BEARING AN UNTOLD STORY INSIDE YOU."

MAYA ANGELOU

What's our Story?

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What does an Ambassador Look Like?

Training Others Be a resource who provides tools and models for others

- Communicate new ways of doing things without insulting the status quo
- Focus on behavioral change over procedural information
- Advocate for staff of restaurants and stores to recognize and interact comfortably with someone who has dementia

Empowering Others Be a positive advocate about change and innovation

- Encourage others through modeling successful strategies with openness about customization
- Create opportunities to share stories, challenges and build community with caregivers

Supporting Others Be open to questions, and comfortable with discomfort

- Ask others questions you clearly have both the *time* and *interest* in listening to the answers to
- Create forums, discussions, panels and other avenues to connect people to share best practices

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Ideas to Engage Residents, Families & Community Members

- Start or sponsor a caregiver support group -- options exist to receive free training and resources through the Alzheimer's Association
- Host, join or participate in a community forum or symposium with speakers to support caregivers of folks with dementia
- Create a network of families willing to exchange information to offer one another guided support
- Plan events like memory cafés, which offer respite to caregivers and engagement to those being care for

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Overcoming Resistance

INSANITY is doing the same thing, over & over again, but EXPECTING different results

- Help people find comfort in uncomfortable situations – if they seem overwhelmed a simple physical touch can help calm them
- Don't talk about people who are in front of you as if they are not in the room
- Provide honest reflections of dementia to help overcome the stigma
- Offer people reminders from the perspective of living with or caring for someone with dementia -- make it easier for others to comfortably interact so they don't withdraw

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Careful Corrections When Others Mean Well

- Try to laugh together about misunderstandings and mistakes -- it can help.
- Humor can help create closeness and may relieve the pressure -- ensure people know you are laughing *with* and not at them
- If it seems one hasn't understood fully, rephrase the question or statement and check for understanding through reaction and body language
- Do **not** correct people with dementia or argue with them about insignificant facts, thus often embarrassing or shutting them down
- Politely call out friends/ family members who may shy away from spending time with someone after a dementia diagnosis
- Encourage others to continue to invite the person with dementia, wherever appropriate to safe social gatherings where they can feel included

Be the person that makes others feel included

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Adapted from Alzheimer's Society, 2020

Commitment Exercise

- Close your eyes and picture a wonderful moment communicating with someone you care about who has dementia
- Envision adding a new comforting memory – what does it look like? Why is it powerful?
- Write down a list of questions and alternate ideas aimed to spark this new comfortable memory
- Decide on three different times and days to try to inspire this moment
- Give yourself room to be angry, frustrated, disappointed or confused
- Give yourself room to celebrate your success
- Write down trends you observe about questions that seem to spark positive reactions from those you interact with



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Sources Consulted

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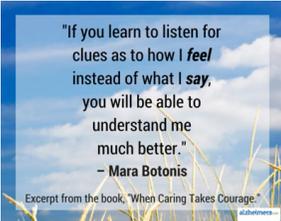
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When dealing with a loved one with dementia, remember the person not the disease.

When dealing with challenging behaviour, remember it's the disease not the person.

@porthdementiafriendly



"If you learn to listen for clues as to how I *feel* instead of what I *say*, you will be able to understand me much better."

– Mara Botonis

Excerpt from the book, "When Caring Takes Courage."

"Don't think of people with dementia as not having abilities. They have an ability to feel and interact and we need to try and enter into their world."

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