

OHCA 2015 Convention

PROGRAM NAME: COMMUNICATING WITH RESIDENTS WITH DEMENTIA AND THEIR FAMILIES

PRESENTED BY:

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Session Objectives

- The participants will acquire knowledge of the communication challenges in Dementia, especially Dementia of the Alzheimer's type
- The participants will comprehend the importance of verbal and non-verbal communication strategies that are therapeutic and emphasize individual relationships in resident-centered care
- The participants will be able to demonstrate knowledge of ways to use communication in dealing with behaviors of residents with Dementia of the Alzheimer's type and know how to communicate with their families
- The participants will be able to apply their knowledge of communication guidelines and behavioral intervention/prevention strategies in devising solutions in small groups for behavior problems and challenges in diverse case studies for residents and their families in long term care settings

Session Objectives

- The participants will be able to demonstrate knowledge of the communication approaches with families of Residents with Dementia/Alzheimer's Disease
- The participants will identify issues that contribute to a family's frustration, distress, and anger that is directed towards the staff caregivers
- The participants can apply their knowledge of communication guidelines in identifying strategies that can bridge family communication gaps and challenges
- The participants will be able to practice devising solutions in small groups for diverse case studies in finding solutions to family challenges in long term care settings

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REFLECTIONS ON AGING

- What is the age of the oldest person you know?
- What are older adults looking for in our care services?
- What are their hopes and dreams ?
- How are we helping to fulfill the hopes and dreams ?

REFLECTIONS ON AGING

- Mark with an X the number representing the age you think is OLD.

• I I I I I I I I I I
 • 40 50 60 70 80 90 100 110 120

- WHY DID YOU CHOOSE THIS AGE?-----

REFLECTIVE EXERCISES

- WHEN I AM OLD, _____

- IF I HAVE DEMENTIA, _____

Role playing in communication

- Mrs. Elizabeth Jones is 90 years old and a resident who cannot sit still. It's affecting her nutrition, since she's agitated at mealtimes and leaves the dining table to go see her "mom".
- Mrs. Jones: "I'm sorry I cannot stay for lunch. I'm meeting my mom for lunch."
- The Nurse has to persuade her to stay and eat.
- Nurse: "Liz, your mom called and said she's running late and will come after lunch. Why don't you go ahead and eat and your mom can join us?"

Role playing in communication

- Mrs. Elizabeth Jones is 90 years old and a resident who cannot sit still. It's affecting her nutrition, since she's agitated at mealtimes and leaves the dining table to go see her "mom".
- Her daughter, Jane, visits her at lunch a few times a week.
- Jane tries to help her Mom to eat. She has snacks and finger foods with her. Mrs. Jones eats very little and walks away from the table and wanders in the hallway.
- Jane asks the Social Worker for a Care Plan meeting with the Registered Dietitian. In the meeting, she complains about her Mom's weight loss and states that "her Mom is starving". She is very emotional and says that her Mom's care is bad. She says she will move her Mom to another community if her care doesn't improve.
- IDT draws up a plan and the Social Worker agrees to meet with her monthly.
- What are some strategies to work with Mrs. Jones' daughter, Jane?

BASIC STEPS OF VERBAL AND NON-VERBAL COMMUNICATION

- VERBAL: Get the resident's attention by calling their name
- Use simple words- eat, sleep, talk; Use simple sentences and give one direction at a time; always approach the resident at eye level
- NON-VERBAL: Maintain eye contact; Use facial expressions, body language; Use a calm consistent approach
- STYLE: Do not whisper; Talk face to face; speak in quiet tones, take resident to a quiet place

SIX R'S OF DEMENTIA CARE

- REASSURE: Reassure the resident that she/he is safe and if an outburst occurs, assure that you understand the distress
- REASSESS: When change is observed or when intervention no longer works, do not assume that changes are due to resident decline
- RECONSIDER: Consider the meaning of what the resident says or does in their context and their point of view

Six R's OF DEMENTIA CARE CONTD....

- REDIRECT: identify escalating behavior that may lead to an outburst and distract with conversation, activity, walk
- RECHANNEL: Find a way for the behavior to occur in an acceptable manner e.g. wandering on a path
- RESTRICT: Always focus on SAFETY AND HEALTH and stop behavior from occurring

SIX R'S OF FAMILY INTERACTION IN DEMENTIA CARE

- REASSURE: Reassure families that they are safe and their loved ones are safe, and if an outburst occurs, assure that you understand their distress, and it will not be held against them or their loved ones
- REASSESS: When issues are brought up, re-examine them again, even if the issue has to be re-visited
- RECONSIDER: Consider the meaning of a situation from the family's point of view

Six R's OF FAMILY INTERACTIONS CONTD....

- REDIRECT: Encourage the family to look at the big picture of their loved one's adjustment and overall well-being
- RECHANNEL: Request the family to get involved and remain active in the life of their loved one in a variety of ways
- RESTRICT: Always guard against any manipulative behaviors of the family to get their own way and make the staff do what they normally would not do

Factors that contribute to Family Distress: Loss and Grief

- Experiencing the loss of a loved one while the loved one is still there
- Dealing with the loss of the relationship
- Going through the five stages of grief: Denial, Anger, Bargaining, Depression, Acceptance
- No right or wrong way to experience grief or no time limit
- Person with Dementia/Alzheimer's Disease is gradually disappearing (e.g. analogy of a car with no brakes)
- Loss of friendships and community interactions
- The diagnosis of Dementia, particularly Alzheimer's Disease, affects the whole family who deals with this loss

Factors that contribute to Family

Distress: Fear and Anxiety

- Fear and anxiety is common, particularly fear about the future and the cost of care
- Anxiety about the future and the disease process
- Feelings of being abandoned by the person with Dementia
- Dealing with a loved one with memory loss is a frightening experience, since connections are formed and held together by shared memories
- Anxiety of dealing with family dynamics in families where members are not on the same page
- Fearful about the demands posed by the loved one with AD

Factors that contribute to Family

Distress: Guilt

- Guilt is a powerful emotion that close family members feel about their loved one's diagnosis of Dementia
- Family members, spouses or children, make sacred promises of providing caretaking in the home
- Many families are in denial about the illness of loved
- All families have some degree of dysfunction, and it is the degree of dysfunction that is different in every family
- Families, who are in denial, also experience guilt and will often make excessive demands and have unrealistic expectations

Factors that contribute to Family

Distress: Anger

- Family relationships are complex and always have on-going unresolved issues
- Caregiving or advocacy is difficult with unresolved family issues (e.g. families with history of Alcoholism or domestic violence)
- Families with issues of unmet expectations and anger can also impact caregiving
- Even in stable family lives, there are issues of fairness and equality that can cause disharmony and cloud judgement in giving care to a family member with Dementia

Person-centered communication with persons with Dementia

- There is a great variability in cognitive abilities of persons with Dementia throughout the day.
- At times, the person with Dementia may be able to respond to normal conversation. At another time, the brain may not be functioning to process information in a sequential order for a conversation.
- It is vital to know each resident, their likes, and dislikes and the best time of day for each person.
- There is no substitute to knowing each resident for successful communication with persons with Dementia.

THE REASONS FOR COMMUNICATION PROBLEMS

- The word “Dementia” is derived from Latin and literally means “out of one’s mind”.
- Dementia is a group of diseases, all of which lead to a permanent loss of neurons in all parts of the brain.

Results

- The result is the following:
- Diminished intellectual capacity and performance
- Impairment of short term and later, long term memory
- Loss of social activities and relationships
- In varying degrees, all dementias involve Aphasia.

COMMON AREAS OF DYSFUNCTION

- **LOSS OF SHORT TERM MEMORY:** This is a painful aspect of communication. Avoid saying: Who am I ? Do you remember what happened yesterday? Framing a conversation in context is important:

- “Hello, my name is Basabi, we enjoyed the program yesterday. I enjoy coming to see you everyday. I haven't see you since yesterday.”

COMMON AREAS OF DYSFUNCTION CONTD...

- **LANGUAGE DISTURBANCES (APHASIA):**
Unable to comprehend and express language, or use it properly, making communication difficult

- **WORD FINDING DIFFICULTY (ANOMIA):**
Unable to find the right word and substitute similar sounding words

COMMON AREAS OF DYSFUNCTION CONTD...

- **PERCEPTUAL DYSFUNCTION (AGNOSIA):**
Misinterpretation of environmental stimuli; does not recognize familiar people, objects, judge distance, understand spoken or written language

- **INABILITY TO ORGANIZE MOVEMENT (APRAXIA):** Has great impact on ADL: dressing, eating, bathing

Aphasia

- Aphasia is the inability to communicate, recall, comprehend, express, or define words and concepts.
- The gradual loss of expressive and comprehensive language begins in the early stages of Dementia of the Alzheimer's Type (DAT).
- This leads to problems in care management in the home and long term care setting.
- Communication is also difficult with various degrees of Aphasia

GRADUAL LOSSES IN COMMUNICATION

- As the disease progresses, conversation becomes more difficult, as the word finding ability becomes more severe and more substitutions of empty words are made (e.g. thing, stuff, this, that etc.)
- Missing elements or absent pieces of information becomes more prominent, causing problems with coherence.

VERBAL COMMUNICATION

- By the later stages, verbal expressions become very difficult to interpret because of word and sound substitutions and missing information.
- In the very last stages, non language utterances and muteness may be observed.
e.g. Band Teacher

WORD SUBSTITUTIONS

- When a person with DAT can't retrieve an exact name, he or she may use a related word or several words to explain.
- Instead of pencil, "writer"
- Instead of knife, "cutter"

COMPREHENSION

- Person with DAT sometimes appear to understand more than they can express.
- They may also understand more of what is said to them, if it's expressed in simple words.
- Utilizing nonverbal communication is also important.

DIFFICULTIES

- As communication difficulties progress, it affects the ability to interact with others, and the person is at risk of being "depersonalized".
- After survival, the most basic need is communication with others in life.
- Without the ability to communicate, the person with DAT becomes isolated.

READING COMPREHENSION

- Some persons with Dementia have the ability to read but not necessarily comprehend what they are reading.
- Therefore, it is unrealistic to expect residents with advanced Dementia to read signs and notes and understand them.
- Many older adults have/had excellent reading skills and can read and recite poems, songs, hymns from early learning experiences. Music is always a great emotional experience.

SPECIAL METHODS OF COMMUNICATION

- Special methods of communication are necessary to help Dementia residents deal with their feelings of frustration and anger due to diminished communication skills.
- It can be rewarding for the staff to see that they were able to convey what they were saying, and the residents were able to understand.

Communication and memory

- "Imagine forgetting the beginning of this sentence by the time you reach the end."
- This sentence is very relevant in highlighting memory and its role in communication with persons with cognitive impairment.
- All communication has to be adapted to this context of loss of short term memory.
- The dialogue and exchange have to be short simple sentences in moderate to advanced Dementia. e.g. "It's lunch time. Let's eat".

LEARNING TO COMMUNICATE: 12 STEPS

- Try to focus on emotions and feelings, instead of arguing about facts
- Identify yourself by name and call the person by name
- Speak distinctly and slowly, using familiar words and short sentences: e.g. eat, talk, sit etc

12 STEPS

- Use phrases like let's do this, or let's go there, instead of don't do this or don't go there
- Provide positive reinforcements for residents, instead of negative ones
- If the resident seems frustrated, ask simple questions with yes or no answers
- If a conversation is agitating a person, move on to something else.

12 STEPS....

- Use visual cues and verbal prompts to help
- Utilize a cue for bathroom visits with an appropriate toileting schedule
- Set up supplies/tasks in advance for ADL's in order for it to go smoothly
- Break down complicated directions, conversations, tasks into simple steps using one step at a time

LEARNING TO COMMUNICATE WITH FAMILIES : 12 STEPS

- Try to focus on emotions and feelings, instead of arguing about facts
- Focus on the big picture of overall adjustment of the Resident
- Try to have a dialogue about a common goal: what's best for the Resident

12 STEPS

- Focus together on the Resident's strengths, not just the problems
- Look at areas of agreements and exchange ideas
- Try to identify areas which are going well for the Resident; call families with good news and talk about the good day their loved one/the Resident had
- Look at problem areas with the family and actively listen to their opinions

12 STEPS....

- Find shared solutions to the problems that families bring up
- Discuss the current capacity of the Resident and provide information/education on the Community, its person-centered culture, and its commitment to honor Resident choices
- Look at realistic action plans that are appropriate for the Resident in their current stage of Dementia
- Follow through on the action plan and monitor for effectiveness and continuity
- Suggest participating in the Resident's current life in the Community with special events, weekly programs, monthly highlights and Holiday celebrations

COMMUNICATING WITH FAMILIES OF DEMENTIA PATIENT

- In Dementia care, a second piece of our care giving piece includes family interactions and family communication.
- Families have guilt about placement, leading to anger
- Families need notifications about their loved ones
- All members of the family are not on the same page
- Families are embarrassed about the behaviors of their loved ones
- Help families see that everyone is on the same side: what's best for the resident
- Encourage Support Group attendance for families

STRATEGIES FOR DEALING WITH DISTRESSED FAMILY MEMBERS

- Identify factors that contribute to a family's anger or distress.

- Recognize behaviors in families and staff that undermine resident/patient care.

- Identify strategies that can diffuse challenging behaviors.

Behaviors that Undermine Care

- Verbal and physical abuse – anything insulting or emotionally or physically hurtful
- Manipulation – getting you to do something you ordinarily wouldn't do
- Constant complaints &/or demands
- Denial of illness
- Expecting staff to “fix” everything

COMMUNICATION WITH STAGE ONE AD RESIDENT

- USE SIGNS
- USE LABELS
- USE WRITTEN MESSAGES FOR REASSURANCE AND COMFORT
- THE PWD CAN UNDERSTAND MORE THAN SHE/HE CAN REMEMBER

STAGES OF AD AND ITS SYMPTOMS

- Stage Two:
- Marked memory loss & confusion, Unable to completed simple tasks, Increased restlessness, Suspiciousness, Combativeness, Wandering, Prone to hallucinations and/or delusions, Severe word finding difficulty, Insomnia, Incontinence

COMMUNICATION WITH STAGE TWO RESIDENT

- Compensate for memory loss by providing contexts in dialogue and exchange, e.g. " I'm your friend, Basabi, and I come to see you every morning"
- Break down complicated tasks into clear simple directions, giving one direction at a time

STAGES OF AD AND ITS SYMPTOMS

- Stage Three: Cannot recognize family, caregiver or self, seems unaware of the environment, speech limited to a few words, usually loses ability to walk or care for self, little observable cognitive function
- Do not assume the resident can't hear e.g. Band Teacher

COMMUNICATION WITH STAGE THREE RESIDENT

- Approach the the resident from the front and make eye contact
- Call the resident by name
- Identify your self by your name and get her/his attention
- Use a calm tone of voice and speak distinctly and slowly

What is the resident trying to say:

- Vocalizations such as curses, groans, moans, screams, verbal repetitiveness or verbally aggressive speech, often occur with the resident.
- Working on changing these verbalizations to a communication effort is necessary.

Underlying meanings of vocalizations of the resident

- Physiological needs
- Psycho-social needs
- Health problems
- Sleep disturbances
- Violation of personal boundaries
- Environmental/sensory stress
- Autonomy issues
- Adverse effects of medication
- Frustration with communication efforts

Vocalizations and their underlying meanings

- “ I hurt”.... Pain status, health overview, Treat pain, make more comfortable
- “ I’m tired”: sleep problems
- “ I’m lonely”: feelings of isolation
- “I’m angry”: stressed and sensory overload
- “I’m looking for my mom”: feeling insecure
- “I’m lost”: loss of short term memory
- “I’m sad”: feeling unsafe, overwhelmed
- “ Why am I here”: feeling disengaged

Caring for the person with Dementia

- **Be flexible and keep things simple**
- **Provide a structure and a consistent routine with pleasant activities**
- **Distract and Redirect**
- **Soothe, compensate and reassure**
- **Communicate, non-verbally, if necessary**

BEHAVIOR MANAGEMENT STRATEGIES

- Person centered approach to behavior management for Dementia residents
- Knowing each person's interests, abilities and impairments can lead to good care management
- Dealing with combative behaviors: Trying to redirect the person. Helping the resident to calm down before doing care.

Case Studies in long term care

- 1) Mrs. Harris, 80, refuses to take a shower . Her nursing assistant has tried a few times to take her for a shower and she has refused. Write 3 ways you can persuade her to take the shower.
- 2) Mr. Smith, 75, is always looking forward to Mrs. Smith's visits. He asks the staff over and over again when his wife will visit. When Mrs. Smith arrives, he says to her "when is my wife coming"? This upsets his wife and he still remains anxious about seeing his wife. Find 3 strategies of dealing with the situation.

Case studies in long term care

- 3) Mrs. Andersen, 90, is looking for her sister who passed away when she was 15. She often cries out for her sister "Sue" when she is agitated. Write down 3 ways of comforting her and lowering her agitation.
- 4) Mr. James is very combative during an activity of daily living, especially his showers, or getting dressed or undressed. Write down 3 ways of dealing with his behaviors.

FAMILY ISSUES

- Dementia of the Alzheimer's Type is a family disease, since it affects the entire family.
- Families want skilled staff caregivers who know about the demands posed by their loved ones.
- Families need validation that they are doing the best they can in a difficult situation and wish for reassurances about the care of their loved ones
- Families also expect to be kept informed about their loved ones. The staff have to be careful in communicating with families. It is important not to volunteer unsolicited information about internal issues of the facility, like staff shortages or staff disagreements, since it will lead to the families worrying about the facility's ability to care for their loved ones.

Staff Perspectives in Long Term Care

- Changing Roles
- Changing Expectations
- Doing More with Less
- Lack of Appreciation or Acknowledgement from Residents with Dementia
- Regulatory Burdens
- Family Demands
- Organizational Expectations in Person-Centered Care

WHAT FAMILIES EXPECT

- Accessibility
- Speedy response
- Communication
- Professionalism
- Continuity

WHY FAMILIES ARE UPSET

- Rudeness
- Indifference
- Being ignored
- Unmet expectations/Unrealistic expectations
- Lack of follow through/Continuity

STRATEGIES FOR FAMILIES

- Staff needs to be aware of their own feelings
- Staff should also be aware of their own responses
- Staff should listen to the families and work on a partnership
- Partnerships in care give families a shared responsibility

LISTENING TO FAMILIES WITH EMPATHY

- Allow families to vent
- Address feelings with empathy and understanding
- Be aware of non-verbal communication on both sides
- Paraphrase the dialogue and exchange
- Thank the families for their involvement and devotion

PROBLEM SOLVING WITH FAMILIES

- Clarify the issue /problem by asking questions
- Look at issues to narrow down to specifics
- Explore alternatives and offer choices
- Involve the family in crafting an attainable goal
- Devise a plan of action and follow through

ADDITIONAL STRATEGIES

- Set limits, if and when necessary
- Lower defensiveness
- Listen for emotional distress and offer comfort
- Recommend Support Group

STAFF : Self-Reflection in family interactions

- Staff have to be careful about constantly defending the system
- Staff have to be conscious about not to argue
- It may be difficult but it's important not to personalize family interactions
- Try to not be defensive, make judgements, or be hostile
- Avoid temptation of confiding in families about the Community

WHAT DO FAMILIES WANT

- Families have guilt about placement, leading to anger
- Families need notifications about their loved ones
- All members of the family are not on the same page and they may be concerned about staff perception
- Families are embarrassed about the behaviors of their loved ones and worry about staff judging their loved ones
- Help families see that everyone is on the same side; what's best for the resident and staff consider themselves the second family of Residents and form a relationship with their loved ones

Case Studies in long term care

- 1) Mrs. Harris, 80, refuses to take a shower . Her nursing assistant has tried a few times to take her for a shower and she has refused. Her daughter is always upset about her not receiving showers and cant understand why her Mom does not get her showers. Find 3 strategies to deal with this situation
- 2) Mr. Smith, 75, is always looking forward to Mrs. Smith's visits. He asks the staff over and over again when his wife will visit. When Mrs. Smith arrives, he says to her "when is my wife coming"? This upsets his wife and he still remains anxious about seeing his wife. Find 3 strategies of dealing with the situation.

Case studies in long term care

- 3) Mrs. Andersen, 90, is looking for her sister who passed away when she was 15. She often cries out for her sister "Sue" when she is agitated. When her daughter arrives, she thinks her daughter is her sister and calls her Sue. This upsets the daughter who corrects her constantly. Mrs. Anderson becomes anxious and agitated during the visit and her anxiety last s even after her daughter leaves. The daughter is distraught and often leaves in tears. Write down 3 ways of dealing with the situation
- 4) Mr. James is very combative during an activity of daily living, getting dressed and ready in the morning. Mrs. James is very insistent and tells the staff to force him to get up and be seated in the morning. Mr. James is very angry in the mornings and is anger, tiredness, frustration often continues all day. Write down 3 ways of dealing with his situation.

Case Studies in long term care

- Mr. Spencer is a big baseball star. He played for the Cleveland Indians and the New York Yankees in the 1950's and retired to a farm near his hometown in Ohio. He is a Resident with moderate Dementia in the Community and his son brings his baseball memorabilia including his World Series ring for a Baseball spring opening day event. He tells the Life Enrichment/Activity Dept that they should watch every baseball game with him as part of his Care Plan. Please discuss 3 ways of accomplishing this plan with a shared solution.
- The Jensen family has brought their Mom in advanced stage of Dementia to the Community but will not accept her condition. They requested Therapy services for her and want her to participate in Activities. Mrs. Jensen is frail and cannot sit up for too long. She had hip surgery due to a fall which caused a broken hip and is always in pain. She has 3 daughters who do not want Hospice Services and Mrs. Jensen is still a full code in her Advanced Directives. They suggest plans for her in Plan of Care meetings which are unrealistic for Mrs. Jensen's comfort. Please think of 3 strategies to deal with this situation.

CONCLUSION

- **There is no substitute to personal knowledge about the person with Dementia/Alzheimer's Disease**
- **There is no substitute to developing a personal relationship with the resident**
- **Communication with co-workers is essential to a team approach in care**
- **Treating each resident as an individual and upholding their dignity and self-worth is vital to the mission of long-term care**

CONCLUSION

- **There is no substitute to personal knowledge about the person with Dementia/Alzheimer's Disease and their families**
- **There is no substitute to developing a relationship with the family**
- **Communication between staff and family is essential to a team approach in good care for the Resident**
- **Treating each resident as an individual and upholding their dignity and self-worth and treating their family with respect is vital to the mission of person-centered care and long term care**
