Techniques for Communicating with the Memory Impaired

Presented by Sr. M. Peter Lillian Di Maria, O.Carm.
The National Association of Catholic Chaplains (NACC) Pre-Conference
May 30, 2019

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What is Dementia?
• A collection of symptoms
  – Memory loss
  – Cognitive loss
• Losses are progressive
  – Mild Cognitive Impairment
  – Early stage – forgetfulness
  – Middle Stage – disorientation
  – Late or Severe Stage – lost communication and self care
• Losses are irreversible
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Dementia; A diagnosis not a disease

Two things look like dementia but are not:

**Dementia:**
- Acute disorientation
- Changes in consciousness,
- Difficulty focusing attention and concentration
- Often seen after hospitalization or medication change

**Delirium:**
- resident complains of memory loss
- Acts sad or apathetic; is interested in nothing
- May sleep too much or too little

Dementia: A diagnosis not a disease

- Both Delirium and Depression can be reversed if they are reported and treated
- Know the person’s “normal” daily personality – (ask families and other caregivers)
- Look out for and report any changes in the person:
  - Behavior (sudden unexplained agitation or withdrawal)
  - Mood (excessive joy or sorrow, e.g., crying)

Dementia Progresses in Stages

<table>
<thead>
<tr>
<th>Child Growth</th>
<th>Dementia Decline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hold up head</td>
<td>Hold job</td>
</tr>
<tr>
<td>Eat solid food</td>
<td>Read/understand</td>
</tr>
<tr>
<td>React to words</td>
<td>Help dress/bathe</td>
</tr>
<tr>
<td>Speak few words</td>
<td>May speak sentences</td>
</tr>
<tr>
<td>Walk</td>
<td>Difficulty walking</td>
</tr>
<tr>
<td>Speak sentences</td>
<td>Speak only few words</td>
</tr>
<tr>
<td>Dress/bathe self</td>
<td>React to few words</td>
</tr>
<tr>
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</table>
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Models for Staging Dementia: Global Deterioration Scale by Barry Reisberg

1. No cognitive decline
2. Very mild cognitive decline
3. Mild cognitive decline
4. Moderate cognitive decline
5. Moderately severe cognitive decline
6. Severe cognitive decline
7. Very severe cognitive decline

(Reisberg et al. 1982)

Most Commonly Used Staging

We will be using the three-stage model from the National Institute on Aging:

• Early (Mild)
• Middle (Moderate)
• Late (Severe)

(Alzheimer’s Foundation 2019)

Stages of Dementia

Remember...

• No two people with dementia will progress at the same rate.
• The stages of dementia are not absolute!
• Overlearned behaviors are preserved the longest.
• Concentrate on the person’s remaining strengths, not losses.
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**Mild Cognitive Impairment (MCI)**

- **Not dementia**
- Increases the risk of developing dementia
- MCI is a problem with memory, language, or other mental function severe enough to be noticeable to other people; measurable by testing; problems not severe enough to interfere with daily life

**MCI | No Functional Loss**

- Change in short-term memory: problem remembering most recent events
  - Loses things; forgets what was just told
- Depression common
- Conflict with others
- Increasing frustration
  - Has trouble concentrating; takes longer with routine chores

**MCI: Common Issues**

- Change in mood and affect
- Symptoms seen as willful and purposeful
- Problems with employer
- Money management issues
- Driving issues: This can be huge!
- Social participation declines
- Unable to complete routine household chores
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MCI: How Can We Help?

- Encourage evaluation for depression
  - Often refuses treatment for depression
- Obtain baseline for memory loss
- Obtain LTC insurance, if appropriate
- Support both person and family with issues common to this stage

MCI: Level of Care

- Unless there is another comorbid condition, person usually can live safely in the community with support from family or community services.

Designing Programs – Maintaining a Spiritual Life

Pre-diagnosis Stage –

- Maintaining spiritual life/mission with dementia is difficult so 1st job is to avoid mental decline
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Early Stage

Losses of Instrumental Activities of Daily Living

In this stage, people may:
• Forget words or misplace objects
• Forget something they just read
• Ask the same question over and over
• Have increasing trouble making plans or organizing
• Not remember names when meeting new people

(Alzheimer's Foundation 2019)

Early Stage

Common Issues

• Loved ones do not recognize symptoms as early dementia
• Loved ones disagree with approach to care
• Person wants to continue to drive
• Commonly seeks second and third opinion
• Family may seek more than available services or may refuse services
• Finances or inheritances may be a source of conflict
• Conflicting past roles resurface
• Fear of stigma associated with dementia diagnosis

Early Stage

How to Help the Caregiver

• Encourage obtaining diagnosis
• Offer appropriate educational opportunities
• Assess support available within the family and community; identify the primary caregiver
• Encourage making legal and financial plans, including Advance Directive decisions
• Make environment of care dementia safe
• Stop person from driving
• Medicate as appropriate
• Progressively lowered stress threshold (PLST) model as a basis for planning care

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Early Stage

How to Help the Person and Communicate Effectively

- Try to understand the person’s anger and frustration
- Offer support in times of frustration
- Organize and simplify daily routines
- Alert friends, neighbors, merchants, bankers, police, and fire department of person’s condition
- Remember persons with dementia are not doing these things on purpose; it is the disease that causes them to act this way

Early Stage

How to Help the Person and Communicate Effectively

- Listen, reminisce and support
- Divert to more positive topic
- Discuss future living
- Recognize impact of “loss of self”
  - Offer time for recall
  - Agree with, don’t challenge recall error

Early Stage

Level of Care

- Should be able to remain safely in the community with support services if friend or family member assumes the role of primary caregiver.
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Designing Programs –
Maintaining a Spiritual Life

Early Stage –
- The most spiritually difficult stage; those who feel abandoned by God suffer most
- Listen, reminisce & support
- How to discuss the diagnosis, how to accommodate spiritual needs

Middle Stage
Losses of Basic Activities of Daily Living (ADLs)

In this stage, people may have:
- Increased memory loss and confusion
- Problems recognizing family and friends
- Continuously repeating stories, favorite wants (e.g., foods, places, songs, etc.), or motions
- Decreased ability to perform complex tasks (e.g., planning dinner) or handle personal finances (e.g., paying bills)
- Lack of concern for hygiene and appearance

Middle Stage
Losses of Basic Activities of Daily Living (ADLs), continued

- Requiring assistance in choosing proper clothing to wear for day, season, or occasion
- Decreasing awareness
- Increased visual-perceptual deficits and recognition
- Repetitive behaviors
- Decline in language ability
- Resistance to intimacy
- Childlike affect (Piaget in reverse; Reisberg refers to it as retrogenesis)
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Middle Stage Common Issues

• Conflict between caregiver and person surrounding personal care: autonomy vs. need for privacy
• Intimacy issues
• Increased self-absorption, paranoia, or hoarding
• Long-term care placement considered
• Family chasing the magic bullet: “medical breakthroughs”

Middle Stage How to Help the Caregiver

• Continue to offer appropriate education regarding disease progression and services
• Consider long-term care needs, possible placement, and/or support services
• Stress importance of caregiver meeting own health needs
• Be a therapeutic listener and strategist with family
• Help bring family to consensus while making future plans

Middle Stage How to Help the Person and Communicate Effectively

• Give one-step directions
• Limit choices
• Develop rituals: Do things the same way
• Permanent assignments of standard of care
• Encourage person to do as much as able to do
• Approach person as you would a friend
• Remind and repeat gently
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**Middle Stage**

How to Help the Person and Communicate Effectively

- Accept that the person will not talk sometimes
- Limit noise and activity that may be distracting or upsetting
  - Noise vs. soothing music
- Speak softly, slowly and clearly
- Do not argue

**Middle Stage**

How to Help the Person and Communicate Effectively

- Accept where the person is in time and place: “enter the person’s reality.” Our reality has no significance to the person
  - Reality orientation vs. Validation Therapy
- Do not quiz the person
- Use of “sensory stimulation”
- Let them know you are listening
- Memory aids may help: put pictures of toilet on bathroom door, and names of people under photographs to help them remember

**Level of Care**

- Assistance with both IADLs and ADLs necessary
- Cannot safely be left alone
- **Needs 24/7 supervision and care**
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**Designing Programs – Maintaining a Spiritual Life**

**Middle Stage –**
- Accommodate losses in communication and religious expression
- Assess current mental status (it changes daily)
- Stress repetition to avoid fear of what is happening next and gain procedural memory
- Accommodate reduced attention span and ability to remember and focus
- Double up on sensory cues to reinforce memory lapses (e.g. photo, ritual and music reinforcement to cue next steps)
- Simplify the surrounding environment

**Late Stage**

**Late (Severe) Stage**

In this stage, there is almost total memory loss. The individual may:
- Recognize faces but forget names
- Mistake a person for someone else
- Experience delusions such as thinking he/she needs to go to work, even though he/she no longer has a job

(Alzheimer’s Foundation 2019)

**Late Stage, continued**

In this stage, there is almost total memory loss. The individual may:
- Have a strong need for holding something close for tactile stimulation, nurturing, companionship and comfort
- Lose the ability to eat, walk and sit up during this period, may no longer recognize when they are thirsty or hungry, and will need help with all basic activities of daily living

(Alzheimer’s Foundation 2019)
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Late Stage Common Issues

• Palliative or comfort care vs. aggressive treatment
  – Who decides?
• Importance of involving the family in these important decisions

Late Stage How to Help the Caregiver

• Help family with common issues: placement, nutritional treatment, and spiritual concerns
• Continue palliative care approaches through end-of-life care
• Help family through grief work
• Serve as a guide for the family and loved ones through the dying process
• Support discussion concerning funeral and autopsy planning

Late Stage How to Help the Person and Communicate Effectively

• Approach the person slowly
• Treat the person with respect and dignity
• Show and tell before doing a task
• Watch the person’s actions, and eye movements; he can no longer use words so be aware of his “body language” (tense, relaxed)
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Late Stage
How to Help the Person and Communicate Effectively

- Touch the person gently (if they are comfortable being touched), as well as using words, to communicate
- Use sensory stimulation (soothing touch; smells; tastes; sounds; sights)
- Tell the person what you are about to do
- Praise the person’s efforts to do a task

Late Stage
How to Help the Person and Communicate Effectively

- Limited communication, no self-care
- Prepare resident for transition from one activity/environment to another
- Use whole body, not just words, to communicate
- Further reduce non-relevant sensory stimulation to enhance concentration
- If behaviors occur, first check for medical causes

Late Stage
Level of Care

- Totally dependent on caregiver for all ADLs
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Designing Programs –
Maintaining a Spiritual Life

Late (Severe) Stage –
• Prepare for transition from one activity/environment to another
• Further reduce non-relevant sensory stimulation to enhance concentration (use one or two sensory cues only in a modified religious service, e.g., music and incense or incense and “Our Father”)
• Non-responsive or response is muted remember that providing them most often religious sequences can still penetrate verbal losses and offer comfort

Common Symbols

Using these symbols is very helpful in preparing prayers
• Beads
• Water
• Fire
• Light
• Oils
• Vessels
• Candles

Stimulating Senses

• Cross – See
• Music – Hear, speak
• Flowers – See, touch, smell
• Incense – Smell
• Nature – See, hear, touch, smell, taste
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Stimulating Senses

- Prayer services
- Simple
- Provide familiar objects
- Familiar prayers
- Time to share
- Music
- Pray while caring for the person

A Gentle Reminder...

Remember: It is the disease, not the person, that makes him do what he does at any stage!

In Summary Communicating

1. Speak slowly using low tones
2. Use simple words and sentences
3. Ask one question at a time and wait patiently for the answer
4. Remain calm
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In Summary Communicating

5. Give one-step directions
6. Break tasks and instructions into simple steps
7. Show your request by pointing, touching, or beginning the task for him or her

In Summary

• Each stage of dementia has its own challenges, but remember in each stage there is something we can do to guide all those affected by dementia

Resources

Additional resources and reference articles are listed on a separate handout titled:
Dementia & Spirituality
Resources and Reference Articles