

## **DEMENTIA**

- **Dementia is NOT a normal part of aging**
- **Symptoms of dementia can be caused by different diseases**
- **Some symptoms of dementia may include:**
  1. **Memory loss** – The individual may repeat questions or statements, misplace things or lose items, forget names of others, forget appointments or to take medications/pay bills. The person may begin to forget recent events with progression to forgetting events/people/history from longer ago. The individual may show increasing forgetfulness and disorientation (person, place, time). Learning new ideas/tasks and remembering new information is often difficult.
  2. **Difficulty with understanding language and/or using language** – The individual usually displays decreased ability to write or speak. Sometimes the person may not be able to “find” the right word to use in a sentence. They may substitute any word or may wait for someone to assist them or “fill the spot” with an appropriate word. Terms often associated with language deficits may include: word-finding problems, echolalia, confabulation and perseveration.
  3. **Motor skills may become impaired** – The individual may experience difficulty with movement, especially fine coordination and control of the hands and arms. If the individual does show signs of in-coordination and lack of control with movement, deficits may be seen in dressing tasks, eating, writing, opening and closing small/tight containers, etc. Sometimes, a person’s brain doesn’t always tell the hands/body what to do and this can lead to problems as discussed above as well as difficulty with walking, balance, and planning movements.
  4. **Executive functions/Cognitive and perceptual skills decline** – The individual may show problems with judgment, reasoning, problem-solving and planning. Often the person loses the ability to think abstractly and requires concrete or specific messages. A person may require assistance to plan more unfamiliar tasks and organize things to ensure safety/thoroughness. A person with dementia may begin to lose insight regarding consequences of certain actions or non-actions. Mathematical skills often show decline due to attention and concentration as well as the above, making it more difficult to do finances, shopping, money management without assistance. Learning new skills is usually difficult. Familiar, repetitive tasks are often performed more accurately and appropriately for longer periods from the onset of the disease.
  5. **Emotional/personality changes may appear** -- An individual may show decreased awareness of or an inability to recognize stimuli (and at other times an emotional response is likely due to the person’s awareness of the “changes” going on in and around them). There are many behaviors that can be associated with the above including: irritability, anxiety, depression, aggression, withdrawal, paranoia, new/increased confusion, incontinence, and/or changes in personal hygiene, sleep or sexual activity.

## **BASIC POINTS TO CONSIDER**

### **Most people do NOT have dementia:**

- Before age 65, less than ½ to 1% are affected (and of those, it is more commonly due to head injuries, although Alzheimer Disease can occur before age 65).
- After 65, prevalence of dementia increases to about 5-10% of the population.
- After 75, the rate increases to 18-20% of the population.
- After age 85, the rate goes up to 35-40% (some estimates go as high as 50%).
- After age 65, 50-70% of the dementia cases are thought to be caused by Alzheimer's disease.

These low percentages translate into a high number of people with dementia. Currently, approximately 4.5 million people in the U.S. have Alzheimer's (the most common form of later life dementia). This is likely to increase as the population continues to age.

### **Dementia is NOT a disease:**

Dementia is a *diagnostic category* representing some/all of the following symptoms which are severe enough to interfere with daily functioning, noticeable in a person who is awake or alert, and typically progressive if untreated (the pattern of losses may be uneven):

- Memory Loss
- Loss of Judgment
- Loss of Abstract Reasoning
- Loss of Sense of Time
- Change in Emotional Responses
- Problems with Speech and Communication
- Loss of Coordination

### **Many other things can CAUSE dementia-like symptoms BESIDES dementia:**

- Stress/Fatigue
- Malnutrition
- Medications
- Other Medical Conditions (e.g. Depression, Delirium, Stroke, Fever)
- Motivation (or lack thereof)
- Sensory Deficits
- Ageist Expectations

## **HOW CAN YOU TELL WHAT IS NORMAL (AND WHAT IS NOT?)**

### **Signs and symptoms which SHOULD trigger consideration of an evaluation:**

- Progressive cognitive changes (new forgetfulness...)
- Psychiatric symptoms (withdrawal, apathy...)
- Personality changes (inappropriate friendliness, blunting...)
- Problem behavior (wandering, agitation...)
- Changes in day to day functioning (difficulty driving, etc)

**A complete evaluation can give you information regarding:**

- The nature of the person’s illness
- Whether the condition can be medically treated/reversed
- The extent of the disability
- The areas where a person may still function successfully
- Other health problems to be treated
- The social and psychological needs/resources of the patient and his/her family
- Changes which may be expected in the future

**Some evaluative procedures:**

- Complete physical medical exam
- Blood tests (e.g., infection, electrolytes)
- Neurological tests (e.g., MRI, CT, PET)
- Cognitive tests (e.g. MMSE)

**WHAT IF IT IS DEMENTIA?**

**What is the cause of the symptoms?**

Many diseases lead to dementia and they differ in the areas they affect and their symptoms. There are about 100 or so diseases associated with the clinical symptoms of dementia, including:

- |                                      |                                  |
|--------------------------------------|----------------------------------|
| Alzheimer Disease                    | Prion Dementias (CJD, GSS, etc.) |
| Vascular Dementia/Multi-Infarct      | Lewy Body Dementia               |
| Frontotemporal Degeneration (Pick’s) | AIDS/Syphilis Paresis, etc.      |
| Huntington Disease                   |                                  |

**What are the possible treatments?**

- |                              |               |
|------------------------------|---------------|
| Medical (depends upon cause) | Environmental |
| Behavioral                   | Familial      |
| Psychosocial                 | Palliative    |

**Things to Remember:**

- People with dementia are still people
- People in the early stages have many remaining abilities
- People are often AFRAID of dementia
- Care giving can be stressful
- Being cared for can be stressful
- Cognitive losses can impact family relationships and roles
- There *IS* help available

**HOW DO I TALK TO A PERSON WITH DEMENTIA?**

**Improving Your Communication Strategies:**

Communication involves both the sending of messages to others (production) and the understanding of messages sent by others (comprehension). Communication includes not only the words we use, but also our tone and body language. Ways to improve communication include:

**Stop and Receive the Other Person’s Communication:**

- Pay close attention – listen and watch their body language
- Be patient (allow time to respond – do not interrupt or rush)
- Focus on the emotional (nonverbal) cues
- Double check your understanding of what the individual has communicated

**If a Person Can Not Find the Right Word:**

- Encourage the individual to act out the meaning
- Encourage the person to “talk around” what they are trying to say
- Say what you think they are trying to communicate (a person with dementia may be able to recognize words they can not generate on their own)
- Be cautious about correcting “wrong” words (this may only serve to frustrate or embarrass a person)

**If a Person Digresses or Loses Their Train of Thought:**

- Repeat the last words said
- Summarize what has been discussed so far
- Ask relevant questions
- Show respect for the feelings expressed, even if the facts are wrong
- If you do not understand, it may be best to say so

**Improve Your Own Verbal Communication:**

- Think before you speak
- Begin each intervention by introducing yourself, giving your name and your role; explain why you are there; socialize a little
- Explain what is going to happen
- Use short, simple sentences
- Do not use conjunctions (e.g., “and” “but”)
- Be specific, direct and explicit about what you mean
- Use concrete and common words (avoid abstract and fancy words)
- Avoid clichés, idioms, sayings, generalizations, and colloquialisms
- Use proper names and common nouns (avoid pronouns)
- Give the most important information at the end of sentences (e.g. “Do you want to drink coffee or tea?”)

**If a Person is Having Trouble Understanding You:**

- Repeat what you said twice
- Revise and restate using different words
- Avoid logical discussions or debates (instead, respond to feelings the individual is expressing)
- Provide immediate feedback, reassurance and rewards
- Assume that the person can understand more than they can express
- Remember that people with dementia will probably forget, so you may need to repeat yourself

**When Asking Questions:**

- Avoid open-ended questions
- Limit the number of choices possible to two

- Give lots of time for a response
- If needed, repeat or reword questions

### **When Giving Instructions:**

- Break instructions into small steps
- Give one direction at a time
- Allow time for completion of each direction before going on
- Give directions close to when they must be followed
- Give positive directions (what to do rather than not do)

### **Improving Your Nonverbal Communication:**

- Gently get the person's attention by being sure he/she can see you before saying anything
- Approach from front so he/she can see you
- Use more than one of the five senses (e.g., say their name and touch their shoulder)
- Use a calm, pleasant, low-pitched tone of voice
- Use open, friendly, relaxed body language
- Move slowly and gently
- Maintain appropriate eye contact
- Use positive facial gestures
- Respect personal space (do not stand too close or too far away from the person)
- Converse at eye level beside or in front of the person (never behind)
- Use objects and pictures to illustrate your message
- Use physical action to illustrate your message
- When giving instructions, demonstrate action
- Be aware of the person's culture
- Be sure that your verbal and nonverbal communication matches
- Keep trying

### **Additional Things to Remember:**

- A person with dementia is still a person with thoughts, feelings, and needs
- A person in the early stages of dementia has many remaining abilities
- A person with dementia may understand much more than they can communicate
- A person with dementia will often understand non-verbal cues long after they can understand verbal communication (so tone and expression matter!)
- Often times the experience (e.g., a pleasant conversation) is more important than the content (accuracy and reality can be overrated!)