

Sheila's note: This is a very useful document written by Jane Tygesson last spring in anticipation of our new program for people with memory loss.

DEMENTIA

DOES NOT MEAN YOU'RE GOING CRAZY!

Picasso – “As one grows older – art and life become one and the same.”

Dementia is not a name for a particular disease. The word dementia refers to a group of symptoms which include forgetfulness and the inability to reason and think clearly.

Several different types of Dementia:

Alzheimer's Disease: irreversible/intellectual impairment from forgetfulness to complete disability. Structural and chemical changes in the brain. 50 to 60 % of those categorized with dementia are in this category.

Vascular Dementia: repeated series of strokes destroys small areas of the brain. Depending on area of the brain damaged, symptoms will differ and correspond to affected area. Can plateau – if strokes are stopped. Previously called hardening of the arteries. 10% of those categorized with dementia are in this area.

Lewy Body Dementia: Microscopic abnormalities in the brain. Symptoms like Alzheimer's but with added Parkinson disease. Visual hallucinations – frequent falls – stiffness – slowness and poor balance. Depression is common. 5 to 10% of those categorized with dementia are in this category.

Frontotemporal Dementia including Pick Disease: Rare form of dementia. Loss of brain mass in the frontal and temporal lobes. Runs in families. 5% of dementia patients have these changes in frontal and temporal lobes.

Precursor :

Mild Cognitive Impairment: This phrase is now used to refer to individuals who have mild memory impairment and who report memory difficulties but who do not meet the criteria for dementia. Mild cognitive impairment probably includes early Alzheimer's disease, the beginnings of other dementing illnesses and the most extreme of the changes that are part of normal aging. Follow-up studies have found that 10 to 12 % of individuals with MCI develop dementia each year after the diagnosis has been made. On the flip side, after five years 40 to 50% remain in the MCI group, they have not progressed or have improved and returned to normal cognition. This group is being closely watched with the hope that early detection might lead to strategies to prevent the development of dementia.

Aging in America in the year 2030

70 million Americans will be over the age of 65. Number of people over 85 will triple.

In 2008 - 5.1 million Americans have Alzheimers. One new case will be diagnosed every 72 seconds – costing the US 200 billion dollars a year.

Percentage of Alzheimers in older Americans:

65 or older 5 – 8%

75 or older 15 – 20%

85 or older 25 – 50%

Familial Alzheimers can start as early as in the 30s.

Early Stage: 1 to 5 years – becomes forgetful – difficulty finding words – depressions – apathy – difficulty problem solving.

Middle Stage: speaking difficulties – difficulties with everyday activities -= inability to understand explanations – changes in handwriting – becomes clumsy – shuffling gait – agitation – delusion – wanders.

Late Stage: Impairment increases – incontinent – physically and mentally disabled

Usually progresses over a period of 7 to 10 years – but can be as fast as 3 or as long as 20.

Can plateau for periods of time.

Brain Changes: Neuritic plaques and neurofibrillary tangles occur in brain. Difficult to diagnose until after death. Deficiencies in neurotransmitter and acetylcholine. Early onset Alzheimers caused by a gene abnormality.

Without the memory of today and an understanding that the past is past – the future ceases to have meaning.*** Which can lead to the following ...

Behavioral Symptoms

Depression	10 – 80%
Agitation	20 – 95%
Sleep Disturbance	13 – 50%
Delusions	12 – 100%
Hallucinations	4 – 43%
Apathy	40 – 70%

What does it look like? Some experience personality changes. Can't remember the right word or name for an object. Becomes clumsy and will walk with shuffling step. Can experience hallucinations – hearing and seeing imaginary things. Some become angry and use swear words that were never part of their previous vocabulary.

Old social skills and the ability to make customary remarks are retained longer than insight and judgement. They can fake it in the early stages.

Severely limited ability to learn new things and understand even simple explanations.

Difficulties retaining what was said – they may be able to repeat a sentence but can't act on what they thought they heard. With progression of disease person may not be able to retain thought for even one minute.

.May be able to read – but not comprehend. Reading and understanding are two different skills.

Loss of coordination – apraxia is loss of ability for message from brain to travel to hands and feet. Feet get stuck – frozen to floor. Loss of balance and frequent falls. Dizziness is common among the elderly and exacerbated by the AZ

Agnosia “to not know” loss of ability to recognize people and things – brain can't put together information – they remember but can't put it together

Loss of internal clock and ability to judge passage of time. Forget daily occurrences – they're not in denial – but simply don't remember something took place.

Paranoia – suspicion – anger – anxiety – restlessness all can be common responses to a world that makes no sense and is totally new and unknown.

People with AD may encounter vision problems including a difficulty to distinguish between similar color intensities, lack of depth perception, prints and patterns may become confusing and low light situations make vision problems even worse. Older eyes take longer to adjust to changes in light.

The past may seem like the present.

Abilities fluctuate on a day to day basis.

Once the ability (coding) is gone – it can not be relearned.

What can we expect as Docents?

When working with individuals with AD we'll find a mixed bag of behavioral symptoms including but not limited to: memory loss, decline in judgement abilities, word finding abilities compromised, poor language comprehension, inclination to go off on tangentials, difficulty with social discourse, loss of inhibitions,

possibility of a catastrophic reaction,* disorientation combined with confusion, agitation, occasional bouts of incontinence, hearing problems and the need to go HOME.

So what's the benefit to these people to come to the Institute?

From the perspective of the alzheimer's patient and their caregiver – it gives them both a place to interact with one another – a meaningful activity for both participants, opportunity for the caregiver to see the receiver in a positive light – gives them both an experience or object to converse about and relate to - psychosocial support system in the group setting – lessens their feeling of isolation – helps both the caregiver and receiver to feel less burdened – less depressed - and helps to avoid moving towards placing the receiver in a nursing home. From the standpoint of the individual experiencing AD – it helps to lower agitation – shown to increase score on cognitive tests – source of well being and self esteem – renewed interest and ability to focus and increases attention span – they become part of a group. Individuals with mild to middle stage AD retain their long term memories which are visually encoded – looking at art triggers these memories and stimulates the imagination and storytelling capabilities that the individual with AD has retained.

What's different about this audience? Or actually not different at all!

Use the KISS system – Keep it simple stupid. Realize that you should never dumb down, but be ready to reorient, redirect, repeat and rephrase. Use short sentences with short words. Allow time for response – slow down and listen and then repeat and validate what was said. Encourage narrative – expect off topic responses and go with the flow – allow for time to turn and talk – identify CG and AD as a team – call on them together for answers. Look for non-verbal cues – expect the unexpected ! Expect partial thoughts and be ready to read between the lines. Sometimes the AD will use word substitutions – such as music for piano – using words with similar meanings. The AD may string words or sentences together that are familiar to them but that won't make sense in the situation. At times curse words just sneak out – a strange quirk of this disease – especially following a stroke. Occasionally the AD will repeat and get stuck on a word or gesture – be ready to redirect in a respectful manner. Also, when you are moving your group – the individual may get stuck in one place – unable to move – help them by pointing to a place or object and ask them to move towards that space. There is the possibility of a catastrophic reaction due to rapidly changing moods and a situation which seems overwhelming. Being treated like a child – inability to make oneself understood – being overtired or overstimulated will all contribute to the reaction. An upset person will experience increased loss of ability to reason and think and may become combative in this situation. It's best to have the CG gently remove the individual from the environment to a quiet place to collect and redirect themselves. .

What to expect from the Docent.

Be enthusiastic – use your face and body, but keep your voice calm and gentle. When words fail – use gestures. Use direct eye contact with both the AD and CG. Use simple sentences realizing that what you say, may not be what they hear – be ready to repeat statements. Speak slowly and lower the pitch of your voice. AD may use an incorrect word, as docent you can say , “Oh, did you mean this?” then supply right word and ask if you guessed right. If you don't understand the response, ask person to describe it or point to it. If AD gets lost in the middle of a sentence – help them by repeating the beginning of the sentence again, which may prompt them to remember what they were saying. Wait for responses – look to CG for

help if the AD is stuck – be patient, never rush the process. Maintain a sense of humor and try to appear relaxed, even if you have to fake it. Go with the Flow. Establish an environment which seems safe – routine is very important, as is giving them direction and information about what the tour will look like. Remind the person where they are and where you’re going to take them. Keep steps limited – don’t give the AD a long list of activities – just one step at a time. Remember for these people – life is like coming in in the middle of a movie. They need reassurances on a regular basis.

What would a tour look like?

To begin – a separate entrance to the MIA would be ideal. At this entrance wheelchairs and camp stools would be available. You would immediately greet the participants and give them name tags. In an unhurried fashion – you would form your group of 6 to 7 sets of CG and AD and tell them – in a brief fashion – where they are and what they can expect from the tour.

The tour would be approximately 1 hour long. It would have a theme, which would encompass four objects of art, moving from representation/narrative types towards more abstract examples. The Docent should prepare six or so questions – three basic what do you see and three with art history bent. Realize that movement within the museum would be best if limited – using quiet rooms without additional noise or distractions would be ideal. Know where the closest bathroom is at all times..

When you’re in front of the work to be explored. Give them time to observe. Ask for a description, naming what they see. Taking a visual inventory will help the participants to focus and connect with the art work. From here move towards interpretation – asking them what they think it means. Asking them to give a personal opinion – an evaluation – is the next step. An lastly move towards connecting the artwork to other areas of their lives and perhaps to the art they’ve already seen – if they have that memory capacity. Remember to not create two planes of conversation – include the AD even if they are non-verbal. Touch on nonverbal reactions like nodding or shaking their head to include the nonverbal. Initiate an activity that allows people to converse with one another and then come back to the group. Encourage storytelling and “turn and talk” moments.