

Behavioral Symptoms

Changes in memory and the confusion they bring can contribute to the following problems:

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

Old social skills and the ability to make customary remarks are retained longer than insight and judgment. Thus, in the early stages, disability is not obvious and individuals can get by without notice.

What does Alzheimer's look like? Some people experience personality changes, are unable to remember the right word or name for an object, become clumsy and will walk with a shuffling step. Some experience hallucinations — hearing and seeing imaginary things. Some become angry and use curse words that were never part of their vocabulary.

Individuals with Alzheimer's experience a severely limited ability to learn new things or to understand even simple explanations as the disease progresses.

People with Alzheimer's have difficulty retaining what was said; they may be able to repeat a sentence but cannot act on what they thought they heard. As the disease progresses, a person may not be able to retain thought for even one minute.

They may be able to read, but not comprehend. Reading and understanding are two different skills.

They can suffer a loss of coordination and apraxia, the inability for a message to travel from the brain to the hands and feet. Loss of balance and frequent

falls may occur. Dizziness is common among the elderly and exacerbated by the Alzheimer's.

Agnosia ("to not know") refers to the inability to recognize people and things. The brain cannot put together information. The patient can remember but cannot put the information together in a meaningful way.

Individuals with memory loss lose their internal clock and the ability to judge the passage of time. They forget daily occurrences; they are not in denial; they simply do not remember something took place.

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

People with Alzheimer's may experience vision problems, including the following: difficulty distinguishing between similar color intensities; lack of depth perception; prints and patterns may become confusing. 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.

Communication Tips: Working with People with Memory Loss

Following are communication tips for working with people with memory loss. Thank you to the following organizations for sharing their insights for this book: Docents from the Minneapolis Institute of Arts, staff from the Wilder Foundation in St. Paul, Minnesota, the Alzheimer's Association and StoryCorps.

Advice Shared by Touring Docents Discover Your Story Tours Minneapolis Institute of Arts

- Remember the Five Rs: Repeat, Rephrase, Redirect, Reorient and Reassure.
- Be flexible; have a plan, not an agenda.
- When you meet a group, greet each person by name. Let them all know how glad you are that they are visiting the museum.
- Do not approach anyone from the rear. Come around in front of each person, kneeling if he or she is seated, so you can establish eye contact during the greeting.
- Make eye contact, and speak slowly and clearly.
- Offering your hand for a handshake is good, but remember, arthritis can make this a painful experience. If the participant seems reluctant, simply lay your hand on his or her arm while saying hello.
- Do not call participants "sweetie" or "dear." You are all equals in this process. These tours are non-hierarchical. Focus on relationship-building.
- If you are tense or nervous, the participants will sense this and become anxious themselves. Remember to take a deep breath, relax and smile.
- Ask concrete questions (e.g. "What do you see?" will often be more appropriate/doable than "What's going on in this picture?"). Ask direct questions.
- Engage the senses. Touchable props with textures and scents are very important. Music works well with these groups too.
- You do not have to impart great knowledge. These tours are a vehicle for interdependent discovery.
- Do not refer back to a piece of art participants viewed 10 minutes ago; they may not remember it. Keep the conversation in the moment.
- Slow down. Listen. Let people finish their thoughts. It is okay if you don't get to everything on your tour agenda.
- The value for the participants lies in being present at that moment. Do not worry about how much they may or may not remember.
- These tours are meant to be uplifting and joyful experiences.
- The experiences are about the people – the participants with memory loss, and their spouses, children and care providers. They are not about the art or art history.

Wilder Program Communication Tips

The Wilder program serves several levels of individuals with memory loss who are grouped in specific rooms: Day Room (mental health and mild memory loss) and Great Room (mid-stage dementia). These suggestions are directed primarily for the memory loss group and persons with cognitive deficits.

Wilder Adult Day Health Staff St. Paul, Minnesota

- This group has significant short-term memory, processing and word finding difficulties.
- Processing delays are common. We recommend waiting 40 to 90 seconds for a response from some individuals.
- Fast and loud are not traits recommended with this group.
- We try to unlock the memories in long-term memory loss. This requires using all the senses, especially visual cueing. Bringing props to touch, along with the auditory and olfactory stimuli, helps to access these memories.
- Call each person by name to get everyone to participate.
- Repeat the statement for each person – people with memory loss cannot retain the information from one person to the next.
- Fill-in-the-blank phrases are helpful – “I like to walk _____.”
- Typed information should be large type – at least 14 to 16 pt, and black type on white paper is best.
- Many clients can read out loud. Select short pieces in large print formats. The Wilder staff can identify which clients enjoy reading and those who do not.
- When using repetition with this population, speak in phrases – no more than three to four words at a time. Use words that are familiar – at about a 6th grade level.
- Clients may perseverate (get stuck) repeating a word, idea or action given by another or themselves. Present a different stimulus to help them get them unstuck and find some original thoughts.
- Use open-ended questions or statements paired with the stimulus. Asking for specific facts or figures creates anxiety and distress for the individual with short-term memory loss.
- Large movements using arms and legs help organize the nervous system. This can improve access to words. We often use action movements at the start of group activities to give a language and concentration boost.
- Pretending or imagining something is an abstract concept that most people with mid-stage memory loss can no longer do. They need a multisensory cue to respond to, and sometimes a person to model the action. Example: Hand a participant a bright scarf. Assist the participant to raise his or her hand up and wave the scarf. Ask the participant if he or she can feel the breeze. Ask if the breeze is slow, warm, cool, etc.
- An environment free of outside noise and visual distraction is important for clients' concentration and participation.
- What Does Success Look Like? Smiling – responsive – attentive – lots of laughter – client-to-client interactions – enjoying the process – calm and alert.

StoryCorps Memory Loss Initiative Interview Tips

Here are some tips for interviewing someone affected by memory loss.

- Keep in mind that the goal of the interview is to share general stories and emotions, not to focus on exact facts, names, or details.
- Use short sentences. Try not to combine two ideas. For example, it is best to ask, “How did it feel growing up during the Depression?”— then, later, follow up with “Did you feel poor?” rather than combining the two thoughts.
- Speak at a normal rate -- not too slow, but not too fast.
- Keep in mind that it might take a while for someone to process a question or come up with an answer.
- Be patient. Do not follow up with another question right away.
- A little prompting may be necessary. It may be helpful to provide some information before asking a question. For example, a daughter might say to her mother, “I know you and Dad met at a school dance. I wonder how you felt when you first saw him?”
- You might have to phrase the same question a number of different ways before a person understands it. Here is an example:

“Tell me about your brother John.”

“You and your brother John are so close now. Why do you think that’s the case?”

“It seems as if John has always been your favorite brother. Why do you think that is?”

- Do not hesitate to share some of your own stories about the storyteller with him or her during the interview. Those stories often spark a memory or just delight the person.
- Be general when you ask a question. Instead of asking about the “happiest” or “hardest” times in a person’s life, ask about “happy times” or “hard times.”
- If someone goes off-topic, go with him or her. Sometimes the best conversations happen this way. You can always redirect the person to your original question later.
- Assure the storyteller that it’s okay to ask for clarification. It’s okay to say, “I don’t remember.” You can simply rephrase a question or ask a new question and return to the topic later.
- Be aware that the interview experience might evoke some of your own emotions – emotions you may not have realized were so close to the surface. This will probably bring you much joy but can sometimes evoke feelings of loss or sorrow.
- Enjoy the opportunity to share the stories, thoughts and emotional closeness that comes with this experience.

Using Props and Sensory Stimulators

The MIA Discover Your Story Staff has found that stimulating a variety of senses while touring this population improves participation, focus and enjoyment. The following props are part of our sensory arsenal; everything is easy to obtain and store.

Props work very well to help make a word or an idea more concrete for a viewer. For example, imagine doing a tour of Native American Art and looking at an animal hide that has been painted with images of bison. If you can hand participants with memory loss a piece of hide while the artwork is on view, and tell them that this was the material the artist painted on, the viewers will find it easier to understand what they are seeing.

Picture yourself in front of a painting filled with flowers. Invite the viewer to smell what the artist might have smelled by offering a bag filled with rose petals or lilac. Particular scents are clearly tied to long-term memories stored in the viewer's mind. Smells open up the mind and make the person with memory loss take a deep breath and relax. More oxygen to the brain is a great stimulant.

During our tours, we have also discovered that familiar poetry and verses memorized in childhood often pop up and out at unexpected times. Many individuals in their 70s, 80s and 90s were taught to memorize and recite a wide variety of verses, and this skill comes back even when everyday verbal abilities diminish. On one tour, the group sat in front of a painting with an image of Abraham Lincoln, and one of the individuals with memory loss began reciting the entire Gettysburg Address from start to finish. This individual could rarely put a short sentence together, and yet she was able to recite the entire speech. When she was done, the group gave her a spontaneous round of applause, and she was pleasantly surprised by the response.

Music, like scents, elicits emotional responses from our tour groups. Old familiar tunes like "Row, Row, Row Your Boat" when you're sitting in front of a river scene seems natural and builds community within the group. When the ability to form words and sentences becomes too much, and the level of frustration is high, the ability to remember music remains intact and allows people with memory loss to participate in the tour experience and quite literally find their voice.

Fabrics and other Tactile Props

Satin
Velvet
Lace
Chiffon
Embroidered shawl
Bird's feather
Fur
Animal hide
Beads
Quill pen
Pearls
Sea shells
Leaves
Tree bark
Pine needles
Piece of polished wood
Baseball cap
Hunting cap
Duck call

Scents – Stored in Baggies

Lavender
Cinnamon
Cloves
Pumpkin spice
Pomanders (orange with cloves)
Coffee
Shoe polish
Lilac
Rose
Chocolate
Fresh bread

Poetry

Various poems that tie into a tour's theme

Music

iPOD – downloaded with music that ties in with a
tour's theme
iPOD Player – inexpensive/compact/lightweight –
purchased at Toys R Us
Kazoos

Compassionate Communication

DON'T

- Don't reason.
- Don't argue.
- Do not confront.
- Do not remind them they forget.
- Don't question recent memory.
- Don't take it personally!

DO

- Give short, one sentence explanations
- Keep instructions simple, repeat as needed
- Allow plenty of time for comprehension
- Agree with them or move to another subject
- Accept blame when something's wrong
- Leave the room to avoid confrontation
- Respond to feelings rather than words
- Be patient and cheerful, go with the flow.

Remember

- They are not crazy or lazy. They are saying and doing normal things for someone living with memory loss. If they were saying or doing things to deliberately aggravate you, they'd have a different diagnosis.
- Their reality is now different than yours and you cannot change them. Nor can you control the disease. What you can control is your reaction to it.
- Their disability is memory loss. They cannot remember and aren't aware that they can't remember. They'll ask the same question over and over truly believing it's the first time they've asked.
- They do not hide things; they protect things by putting them in a safe place and then forget they've done so. Do not take accusations of 'stealing' personally.
- They may at times be scared. Each person reacts differently to fear. They may become passive, uncooperative, hostile, angry, agitated, verbally abusive or even physically combative. They will often alter their behavior in unpredictable patterns. Anxiety may compel them to follow you everywhere. They can't remember your reassurances. Keep saying them.

F. GUIDELINES FOR LEAD AND ASSISTANT FACILITATORS

You will always have two facilitators assigned – one as LEAD and one as ASSISTANT. It is too much to ask one person to manage the visit – safely. If a participant needs to have a bathroom break, the ASSISTANT, knowing the LEAD's route, can break away from the group and rejoin without stopping the whole group for 5 or 10 minutes. (Remember, you need to have either a staff member or family member accompany the individual with memory loss to the restroom.) If you need to split the group in order to go up the elevators, each group will have a guide. The guide can determine if they want to split the presentations up, but keep in mind that “simpler is better” with this population.

The LEAD facilitator will be in charge of contacting the health facility. Many times the staff isn't sure which residents they will be bringing along for that particular visit due to the residents' mood and health concerns on the visit day, so it's important that the LEAD facilitator start from scratch in eliciting information. Here are some things you want to talk with your contact about:

Questions for Contact at Memory Care Facility

1. When you make the call to the contact, who may or may not be the activity director at the center, please let them know that they will need to supply one “official” staff member (not volunteer) from the facility per 5 residents. It would be great if they could also supply additional volunteers, but the staff ratio is by far the deal breaker. You can tell them that we've found that especially with the individuals with mid-stage symptoms, a one-on-one ratio is important for a positive tour. This ratio helps to lessen the anxiety level of the person dealing with memory loss, allowing them to truly enjoy their visit. So, if they can invite family members or other volunteers along for the tour that would be beneficial.
2. Please let the contact know that we're counting on them bringing the number of people that were originally confirmed.
3. Ask your contact if they know whether the resident is in the early or mid-stage of the disease.
4. Ask your contact if they need your organization to provide wheelchairs, and if so, how many. If wheelchairs are required – it means we need a volunteer/staff member to push them. If the facility and or LEAD can't find the volunteers, you need to let the facility know so that they will need to adjust their numbers accordingly or get additional volunteers. If the individual with memory loss declines the wheelchair, inquire whether or not the participants can stand for one hour. Let them know we can provide folding chairs.
5. What is the general level of verbal ability in the group?
6. Would they like us to provide listening devices for any members of the group?

7. Ask your contact if they have any residents that like to wander. If so, we could use a heads-up on those participants. Ask the staff member from the facility to keep an eye on them during the tour.
8. Sometimes it's difficult to determine who the person with memory loss is, especially when the facility brings along additional volunteers. So it would be very helpful to have name tags already on the person with memory loss, just their first names, so we know who's who.
9. If your contact knows their people with memory loss well, discuss the possibility of breaking them into groups before they arrive. It can helpful to group higher functioning individuals in one group so that we can adjust the tour to fit their needs.
10. Let your contact know which entrance they will be entering through.
11. Please confirm drop off and pick-up time.

Day of Tour – Guidelines for LEAD and ASSISTANT Facilitator

- Prepare the evaluation forms, postcards, props and nametags. Consider having large umbrellas handy.
- Make sure any listening devices have been charged and are on the correct setting. Do a sound check on each receiver to make sure they're working.
- Make sure the wheelchairs are by the entrance.
- Set out stools for partners to grab and put on the back of the wheelchairs.
- It's important that the LEAD lets the ASSISTANT know their route in case the ASSISTANT needs to break off with a participant (and staff or family member) for a bathroom break. The ASSISTANT needs to be aware of keeping the group together and should be at the tail end of the tour group to keep stragglers moving along.
- Confirm that any locked areas will be opened for your group.
- Once the bus arrives, the LEAD facilitator can go out and meet the bus to find out whether or not they require that wheelchairs be brought out to the bus or if the individuals with memory loss can walk in with assistance.
- If you have enough volunteers, it would be great to ask them to partner with a person with memory loss right from the start. They can introduce themselves and tell them that they will be right along side them for the entire tour. This helps to cut down on the newness and resulting anxiety of entering the building for these people.
- When the residents enter, someone can take their coats and get them a name tag with just their first names on it if they aren't wearing one. During the winter months, it's a good idea to label coats as well since it can be confusing to get them back to their owners. If the memory care staff can help you divide them into groups, it would help to cut down on the chaos.
- Ask the staff if anyone needs a bathroom break. If so, staff needs to take them to the bathroom, not a volunteer.
- If anyone is using a listening device, hand it to the care partner first and have them do a sound check and then fit it on the person with memory loss.
- Once your groups are formed, the LEAD facilitator should take the time to sit down, introduce themselves and welcome the participants. Nothing elaborate – keep it simple and brief. Repetition is good. Tell them again where they are and that someone will be with them at all times – they needn't worry. You may need

to do this several times throughout the visit to reassure the participants with memory loss.

- If you are wearing a transmitter, either turn it off or move the mouthpiece up and away from your mouth while you are moving your group. We've been told it's confusing for the individual with memory loss who's wearing the receiver to hear your voice when you're not in front of them.
- When boarding your groups on the elevators, someone needs to hold the button inside the elevator; otherwise the doors close too quickly. Try to break up the group so that there is a facilitator in each elevator.
- Invite the care partner to sit alongside the person with memory loss. We encourage the LEAD facilitator to sit as well, it seems to work better for eye contact with the group participants.
- SLOW DOWN - listen actively and let them tell you their stories.
- Check in with your group several times during the visit to make sure they can all hear you.
- Please remember, many of these individuals can clearly remember events from 20 or 30 years ago but won't remember what you said a moment ago. It can be frustrating for the individual with memory loss if you refer back to something that occurred ten minutes ago, so keep it in the moment.
- Occasionally one individual will dominate the conversation. You can try to get down in front of them making eye contact and thank them for sharing. Then tell them that you are going to share what they've said with the rest of the group. You can also redirect by asking another participant - by name - a different question to get the conversation going again. You can also ask the care partner to talk quietly with the gregarious individual.
- On the other side of the coin, you may have a very quiet individual. In this case, after making sure that they can hear your voice, you can sit and make eye contact with them and ask them something addressing them by name. By talking to them individually and inviting them to comment we've found many of the quieter participants will open up. If they choose not to participate, you can try a "turn and talk" and invite the dyad to work on a question together.
- There have been instances when an individual is so hard of hearing that the assisted listening devices aren't effective. Ask the care partner to bring along a pad of paper. If the individual can see well enough, their care partner can write out questions during the visit. We had one individual whose anxiety level was very high whenever he visited. Bob continually asked, "Where am I?" and "When am I going home on the bus for lunch?" We knew that Bob had retained his ability to read - he was constantly checking his watch - so we printed a sheet

of paper repeating the answers to his questions and would place this answer sheet on his lap. He stopped asking the questions, was able to focus on the and began offering up comments.

- At the end of the visit, please remember to give the individuals with memory loss a postcard/brochure and to give the staff member in charge an evaluation form.
- We have been told that helping to load the bus is greatly appreciated by the memory care staff. If possible, walk or wheel the residents out to the bus, thank them for coming and say good-bye.

Workshop Scenarios for Early- and Mid-Stage Touring

What would you do in these situations?

- A caregiver totally dominates the conversation.
- When the tour arrives at the museum, you can't tell the participants from their caregivers.
- A participant continually walks away from the group.
- One participant repeatedly asks where they are and what time it is.
- A participant begins to nod off.
- No one in the group is willing to talk.
- A participant needs a bathroom break.
- Multiple conversations are going on while the docent is talking.
- The docent cannot understand the answer from one of the participants.
- One of the participants breaks into song in the middle of the discussion.
- The participant's answer has nothing to do with the question posed by the docent or anything that the tour has been looking at or talking about.
- A participant who has been walking stops dead in his or her tracks and becomes anxious and begins to ask where he or she is.
- A participant in a wheelchair becomes agitated and attempts to get out of the wheelchair.
- During the winter months, you've hung the participants' coats in the coat room and they can't tell you which one is theirs.
- One of the dyads walks away during the tour.

I. SAMPLE EVALUATION TOOL

The following is an evaluation form created for the Discover Your Story tours at the Minneapolis Institute of Arts. This piece is either mailed or given to caregivers with a postage paid envelope following the end of the tour. If the form was not returned follow-up phone interviews were made using these same questions to elicit feedback from the participants

Discover Your Story

To help us assess the effectiveness of the museum's "Discover Your Story" tour program, please take a few minutes to respond to the following questions.

Name (if desired) _____ Tour date _____
Low High

Rate your overall tour experience. 1 2 3 4 5

How well did MIA staff tailor the tour to your needs? 1 2 3 4 5

How effectively did the docent(s) involve you in looking at and discussing the art? 1 2 3 4 5

Did the docent(s) use appropriate questions and language ___ Yes ___ No

Please comment.

What aspects of your visit did your group most enjoy?

Did your museum experience meet your expectations? ___ Yes ___ No

What could we do next time to make your experience even better?

Thank you. We value your feedback.