

Early Stage Town Hall Meeting
Cleveland Chapter Summary

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Executive Summary

The Cleveland Chapter of the Alzheimer's Association, in partnership with University Hospitals Neurological Institute and the Benjamin Rose Institute, held an Early Stage Town Hall event on May 31, 2008. The attendance list indicated that 180 people attended the event, 50 of whom were individuals with memory loss. The event began with short presentations by a panel of professionals specializing in memory loss and persons with early-stage dementia. A structured discussion period took place next, concluding with an open discussion over lunch. The structured discussion led to many participants, individuals with memory loss and family members, sharing their feelings and suggestions in small groups and with the larger audience. Facilitators at the individual tables encouraged participants to share their thoughts, and staff from the local Alzheimer's Association facilitated audience comments by identifying willing participants and offering them the microphone.

The topics for the day centered on *Interactions with the Medical Community, Meaning in Life, Relationships, Independence/Autonomy, Community Resources, and Research*. Persons with memory loss and family members provided personal stories, recommendations, and moments of humor. As participants talked about the aforementioned topics, there were repeating themes throughout several topics. For example, *driving* was discussed in relation to *Meaning in Life, Relationships, and Independence/Autonomy*. Another overarching theme throughout the day was the need for information. Participants mentioned that they often sought information about diagnosis, treatment, and medications; opportunities for maintaining activities and engagement with others; sources of support and services; and information about participating in and the results of research.

The event closed with a Call to Action. Participants were told about upcoming events (e.g., local Memory Walk, local research opportunities) and asked to complete a form indicating what types of opportunities they would like to be made aware of (e.g., Northeast Ohio Early Stage Advisory Council, becoming an Advocate for Public Policy Change). Participants then enjoyed lunch and extended conversation with other participants.

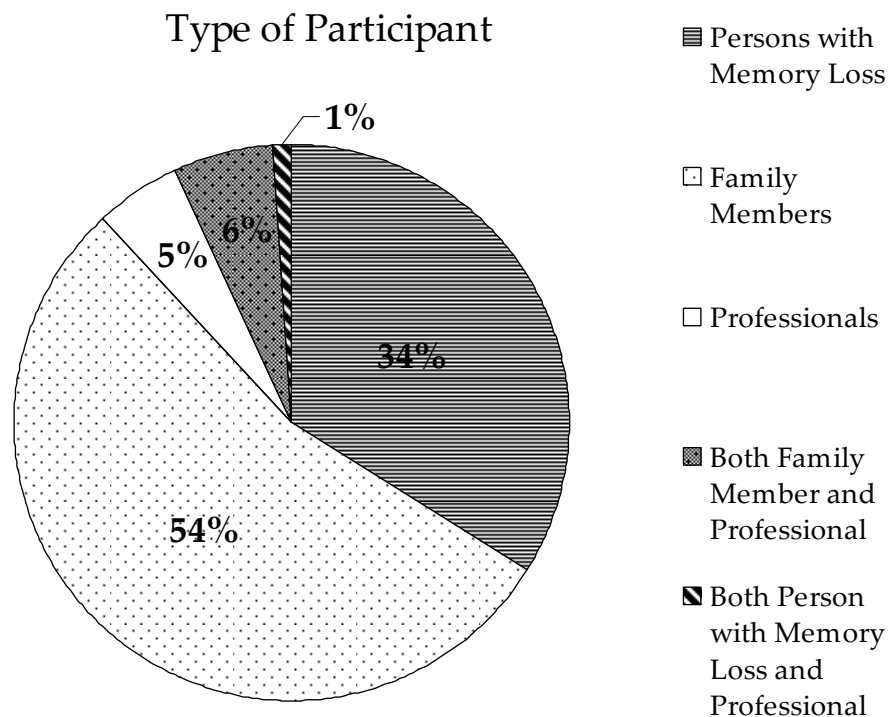
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Description of Participants

One hundred eighty people attended the Early Stage Town Hall Meeting, and 104 of these attendees completed a demographic form. The following is a description of these attendees:

- Persons with memory loss, family members, and professionals were in attendance at the meeting.

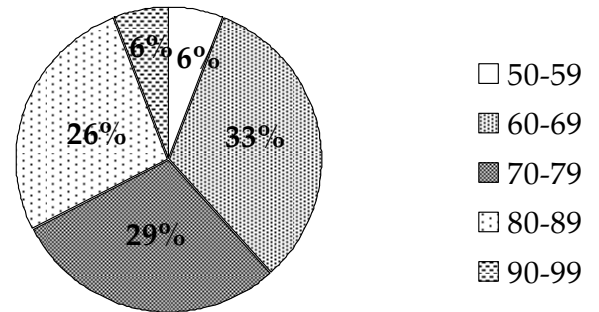


- Thirty-five percent of participants were male.
- There was some variation in the race of the participants:
 - Most (79%) of the participants were Caucasian/White;
 - 18% were African-American/Black;
 - 2% were Hispanic or Latino; and
 - 1% Asian.

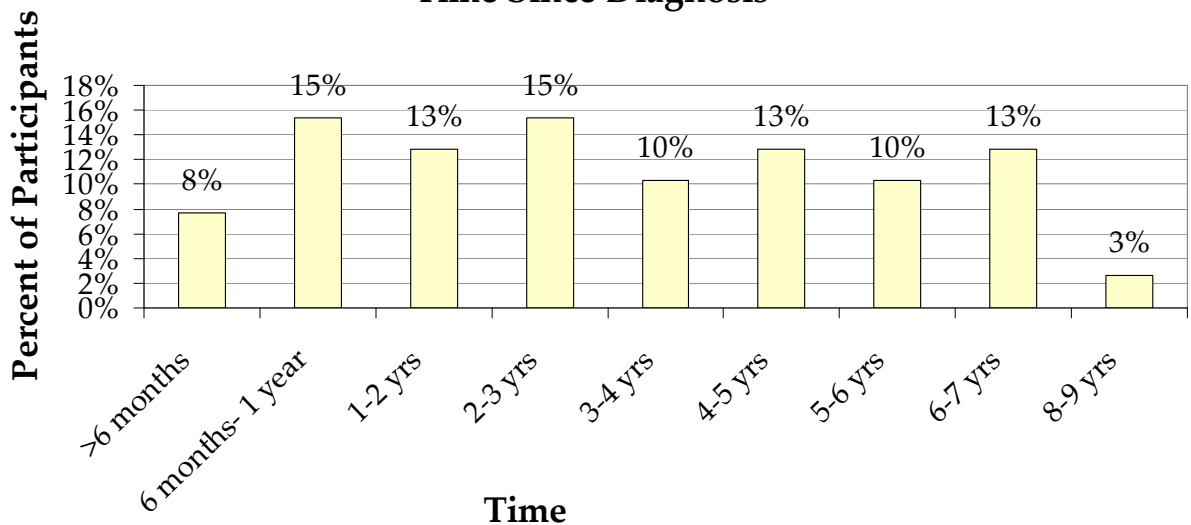
Persons with Memory Loss

- Thirty-four of the persons with memory loss indicated that they had been diagnosed by a physician.
- Most diagnosed individuals had received a diagnosis of Alzheimer’s disease (71%). The next most common diagnosis was Mild Cognitive Impairment, followed by diagnosis of a stroke.
- The following diagnoses were also noted:
 - Frontotemporal lobe dementia;
 - senile dementia; and
 - vascular dementia.
- The ages and length of time since diagnosis varied greatly for persons with memory loss.

Age of Participants with Dementia



Time Since Diagnosis



About 70 of the 104 participants who completed the demographic form also responded to the following question: *Before today's event, which programs, services, and research projects related to Alzheimer's disease or related dementias have you been involved with?* A portion of these individuals (about 14) had not been involved in anything before the event. The other individuals reported prior experiences in the areas of: (a) services; (b) education; (c) research; and (d) volunteering/advocacy.

a. Services

Services people mentioned ranged from support groups, to medical services, to alternative services. Support groups included specific groups people had attended (e.g., Sally Ollerton's group, "Alzheimer support group in Westlake") as well as meeting with others at the annual Memory Walk. Comments about medical services included names of local physicians (e.g., "we have seen Dr. Wayne two times," "Geriatric Assessment Program at Euclid Hospital with Dr. Suh"). One particular alternative service noted was reiki.

b. Education

People reported various examples of education experiences, including attending forums (e.g., caregiver training weekly seminars, "Just the Facts" presentation), participating in the Learning Together series, and readings (e.g., brochures, reading material, "I have also gathered lots of info from the Alzheimer's Association").

c. Research

Most of the research noted was psychosocial research conducted through the Benjamin Rose Institute (e.g., ACES project, ANSWERS project). There was mention of participation in genetic research through the University of Michigan.

d. Volunteering/Advocacy

A few of the participants noted that they had participated in volunteer and advocacy activities related to Alzheimer's disease or dementia. These activities included speaking on behalf of other's with memory loss in Washington, DC and participating in meetings.

Structured Discussion

I. Interactions with Medical Community

Topics for discussion in this section as well as responses were broken down in the following sections: *what has been the best aspect of your health care experience; what recommendations do you have to improve the health care experiences; what suggestions do you have that could make your medical interactions better; and what has been your experience with medical research.* The discussions prompted by these questions centered around three specific themes: (a) the diagnosis experience; (b) communication issues with doctor; and (c) medications and medical research.

a. The diagnosis experience

- i. One major theme is this area revolved around the lack of support many persons with memory loss felt after receiving their diagnosis. Post-diagnosis, many persons with memory loss felt as if the diagnosis was dropped on them with no further guidance, assistance, or hope.
- ii. Participants offered such quotes as: "Doctors give diagnoses. But do not offer practical suggestions"; "Need to increase awareness of help available and address the emotional side of the diagnosis." Others mentioned the importance of being able to ask questions of the physician without feeling rushed or intimidated. One participant mentioned "most doctors aren't open to assertiveness; I was told I ask too many questions." Yet another stated "There was no mention of counseling or support. After such a terrible diagnosis, we left and we were devastated."
- iii. Another major theme was the importance of addressing the emotional issues of receiving a diagnosis of dementia and placing an emphasis on treating the whole person, not just the medical component. For example, one person with memory loss suggested "I think less 'pigeon-holing' people into narrow parameters would be a good thing to be considered. Every person is an individual with unique differences. We are not rubberstamped robots. Please be kind, you too will be old someday."

b. Communication issues with doctor

Participants discussed aspects of their doctor/patient relationship. Interactions with physicians tended to be viewed more positively when the physician offered hope and possible treatment options. In addition, when the

doctor made time to answer questions from the person with memory loss and his or her family members is when the patient felt best about his or her experiences.

- i. Positive comments from persons with memory loss included: “my doctor gives me hope that things will get better, even though there’s no magic bullet, there is hope for one.” Another stated “my doctor always follows up on things and doesn’t mind that my sister comes with me to appointments.” A family member commented “We have a doctor come to the home, brings his own equipment. He gives exercises for my loved one to do. We had gone to a well known doctor and were unhappy. The home doctor is more convenient, more hopeful. The doctor is trying to get him interested in piano again.”
- ii. There were many comments surrounding the challenges faced by persons with dementia and their family members when interacting with the medical community. A common theme throughout this section was the feeling of being abandoned after the initial diagnosis and not knowing where to turn next. “Now we only see the nurse practitioner and not the doctor, who do I call, what doctor if there is a sudden change?” “We felt as if the doctor told us ‘you failed the test, goodbye.’”
- iii. Suggestions given by persons with memory loss to improve and enhance medical interactions included:
 - Doctors need to communicate better with patients; that would include making better eye contact and being more sensitive when discussing prognosis.
 - Care needs to be more coordinated, e.g., doctors when giving the initial diagnosis should provide patients with the resources they need to cope with the emotional aspects of being diagnosed with memory loss.
 - Nursing staff in hospitals need to understand and be educated about Alzheimer’s disease and how it impacts care.
 - Doctors need to involve family members in gathering more information about the patient, especially during an emergency.
 - Primary care physicians should refer more to specialists if unsure of diagnosis; many people commented on how much time, energy, and money was wasted in order to get an initial diagnosis. This would have helped the person with memory loss get the treatment he or she needed more quickly.

- Doctors should be leaders and the head of the team that treats the patient and his or her family. “A good doctor has a sense of humor, diminishes fear, becomes like a buddy, but is serious about my condition. He is our quarterback.”

c. Medications and medical research

Discussion surrounding medications and medical research often occurred together, and the following themes were identified:

- i. Education about medication options: Both persons with memory loss and their family members had concerns about not knowing how the medications work. One person suggested “Give more information about the drugs and how and why they work for Alzheimer’s disease.” Another person with memory loss commented on how the doctors should provide more education about the medications they are prescribed: “I live alone. I am learning. But I still don’t know enough.” The importance of a doctor who explained things in terminology that they can understand was discussed. One person reported a positive experience with a doctor who explained the use of medication in layman’s terms: “Aricept does not make you better, but helps to keep you at the level you are at.” Others called for more education about new treatments on the horizon as a way to continue to hope for things to get better in the future.
- ii. Side effects: Experiencing unpleasant side effects of medications for memory loss was discussed as a major cause for discontinuing their usage. Participants noted they would often find the medication was not helpful, but would give them unpleasant side effects. “I stopped taking my medication and when my family found out I restarted, with negative results.” “I think Aricept caused my weight loss and I discontinued it.”
- iii. Research: The opportunity to participate in research was identified as important by persons with memory loss throughout the discussion. However, many commented on how difficult it is to get information on studies that are going on and being informed about opportunities. “I need more research provided – big issue!” “I would like to do research, but with whom?” “It would be helpful to have a location to get info about good research, doctors, and clinic.” Others felt too overwhelmed to participate in research with everything else going on

in their lives. "Research creates too much confusion for me and my family."

II. Meaning in Life

Participants were asked to respond to two questions regarding meaning in life: *What gives your life meaning (e.g., volunteering, activities, family)* and *What could be done to give our life more meaning (e.g., by you, by others, specific activities)*? Four main themes were expressed regarding these questions: (a) activities; (b) social interactions; (c) hobbies; and (d) how to give or maintain meaning in life.

a. Activities

The most common responses about meaning in life were about activities. An overarching idea here was the need to "keep active." Specific examples about activities were volunteering/working, helping others, church/faith and various other activities in which people were engaged.

- i. Participants reported working at local grocery stores, volunteering with children, being a "reading tutor," fundraising, and working with a foodbank.
- ii. Some participants indicated that helping others gave them meaning in life because they are "able to do something for somebody else."
- iii. Observance of one's faith and religious beliefs (e.g., attending church, reading the Bible) was mentioned several times as giving meaning to life.
- iv. A diverse list of other activities was offered as ways individuals found meaning in life. Some of these activities included: driving, attending group meetings (e.g., Learning Together), remaining independent, completing household chores, and attending adult day programs.

b. Social interactions

Another important area that people indicated gave them meaning in life was social interactions. Participants noted three groups with whom they were social and interacted: family, spouse, and friends.

- i. Participants noted the importance of "staying social with family" and that "without family there is no 'life' just 'existence.'" It was also suggested to teach the family about the legacy of the person with memory loss.

- ii. Persons with memory loss highlighted the importance of their spouses: “my wife, very supportive” and “having a wife that cares about me.”
- iii. Interactions with friends were also emphasized as participants noted that they “remain in constant contact with friends” through communication and visitation.

c. Hobbies

Participants mentioned many hobbies that gave them meaning in life, including: animals/pets (e.g., “taking my dogs on walks”), nature (e.g., “being outdoors”), reading/ writing/ journaling, gardening, fishing/ hunting, exercising (e.g., golf, tennis, walking), music (e.g., listening, singing), movies, dancing, and other activities (e.g., Rotary Club, peace activities).

d. How to give or maintain meaning in life

Individuals offered many ideas of how to gain or maintain meaning in life. These ideas centered on “having a purpose in life,” activities, volunteering/ working, logistical issues, and other suggestions.

- i. Ways to assure that the person with memory loss has a purpose in life included allowing that individual to remain independent as long as possible and include him/her in decision-making activities. It was expressed that persons with memory loss “need a purpose each day” and “need to still feel needed.”
- ii. Activity ideas were suggested that allow the person with memory loss to “keep busy doing something I will enjoy and get some pleasure.” It was suggested to “try different things” but to also identify activities “tailored to their abilities and expertise.”
- iii. It was expressed that volunteering was a “way to feel useful” and one individual indicated that they “helped with activities at Day Away [day care].”
- iv. Recommendations were made regarding logistical aspects of enhancing meaning in a person’s life. For example, having “better coordination of resources available” and “looking for activities in proximity to our area for ease of transportation.”
- v. Participants also offered some very practical thoughts about what it takes to maintain meaning in life: money, “get memory back,” and “continuing family support and understanding.”

III. Relationships

Town Hall attendees were asked to answer two questions regarding their relationships and roles: *How have your relationships and roles changed since your diagnosis (e.g., positive experiences, negative experiences/challenges)?* and *What could be done to help you with the changes in your roles and relationships (e.g., by you, by others, specific activities)?* Five main themes were expressed regarding these questions: (a) role changes; (b) brought people together; (c) negative changes to relationships; (d) no changes/see no difference; and (e) how to help with the changes.

a. Role changes

The most common reaction to the question about relationship and role changes was about the changes in roles. Within this theme there were two distinct types of comments, comments about changes in activities and comments about the reversal of roles.

- i. Many attendees mentioned changes in activities since the diagnosis. Some of these changes related to the person with memory loss's "inability to continue managing finances, make plans independently, etc." and the need to depend on others for assistance more. The loss of driving was often mentioned as an activity change (both positively and negatively). In addition there were comments about being less social and engaging in fewer social activities: "less conversation because of loss of vocabulary"; "I'm not motivated to go out. I'm not interested in people"; and "person with memory loss stops participating in groups/activities."
- ii. Several participants mentioned that a reversal of roles had occurred typically between the person with memory loss and his or her caregiver/family member. This role reversal was explained by one person with memory loss: "my wife has taken over the responsibility of all bill paying which I had previously done for our entire marriage until about 5-6 years ago." Family members/caregivers expressed that the roles had shifted in that the caregiver "becomes more like a parent" or the relationship is "parent-child now, not spouse."

b. Brought people together

Several participants expressed that since the diagnosis “others have shown a depth of love that we hadn’t experienced before.” These positive comments often focused on the relationship between spouses, family members, and friends.

- i. It was expressed that spousal relations had grown closer, and that “our love for each other grows stronger.” One family member/caregiver expressed that the couple’s dependency on each other actually helped them as a couple.
- ii. Similar to the perspectives on the spousal relationship, it was viewed that there is a closer relationship with some family members. It was expressed that “family is giving input and following up on promises.”
- iii. Also, there were a few comments about the “good support of friends who understand.”

c. Negative changes to relationships

There were almost as many negative changes to relationships as there were expressed positive changes. It was noted that “no one wants to be bothered.” Sources of negative changes were again expressed regarding the relationship between spouses, family members, and friends.

- i. Many family members/caregivers expressed a negative change in the relationship with their spouse since the diagnosis. One person indicated that “we don’t even share the same bed anymore.” Others expressed the change as “losing a mate” or that the spouses were “no longer equals.”
- ii. It was also noted that some family relationships have become estranged because “family backs off.” Children and family either don’t understand what is happening or they can’t deal with the situation.
- iii. Also, there were a few comments that “many friends have walked away” and “past friends ignore us.”

d. No changes/ See no difference

Some participants expressed that they had not experienced any changes in their activities and roles because “nothing too much has changed” and “haven’t lost much yet.”

e. How to help with the changes

Participants offered a range of suggestions about how to help with role and relationship changes. Many people said that support groups and networking (e.g., through church) were helpful. Others indicated the need to “include the person with memory loss and not talk around them,” to not “not refer to the person with memory loss as ‘child like’ because it is offensive,” and to continue to recognize the person for what he or she can do and not for what he or she cannot do. It was expressed that keeping active and engaged was important. Additional suggestions focused on communication among family members (e.g., a family blog, speaking up, and asking for help), having the person with memory loss and the family member take short trips, and maintaining a sense of humor and love for life. A couple of family members expressed that grieving was another method that helped them with the changes.

IV. Independence/Autonomy

Town Hall attendees were asked to answer four questions regarding independence and autonomy: *How has your independence changed since your diagnosis (e.g., positive experiences, negative experiences, as related to your finances)? how do you balance your independence with safety? what strategies have you used to address change in your independence? and what could be done to help you with changes in your independence (e.g., by you, by others, specific activities)?* Three main themes were expressed regarding these questions: (a) Loss of independence; (b) Safety issues; and (c) Techniques for staying independent.

a. Loss of independence

Although many persons with memory loss who participated in this event remain independent on many levels, some expressed a general loss of independence. “I have lost all of my independence, I depend on my caregiver 100% of the time.” Otherwise, responses were broken down into two major themes: Driving and managing finances.

- i. Driving: As many attendees agreed, difficulty with driving and losing the privilege to drive are directly related to feelings of losing independence. Some commented that they continue to drive but have to be more careful and only drive shorter distances. “I’m more cautious, I don’t go as far as before.” Others stated that their doctors told them they were not allowed to drive anymore. Some agreed to stop driving on their own after they

recognized it as a safety issues or after getting into accidents. "I gave up driving after accidents. I did not remember first accident and had another shortly after. Now I know I should not drive."

Others were extremely angered by being told they were not allowed to drive, and the way they were told contributed to the feelings of anger.

"Has the doctor ever been told he's not allowed to drive?"

Overall, losing the ability to drive also contributed to losing the ability to go places alone, which created a feeling of dependence.

- ii. Managing finances: A common theme was the family taking over managing the finances after the person with memory loss started having difficulty.
 - Some individuals who always managed the household finances felt it was a huge loss to no longer be able to complete this task independently. Some wanted to continue to try and manage this task but felt afraid to make decisions on their own or feared making a mistake. All of these things contributed to a loss of independence.
 - However, others were comfortable with having a family member take over managing the finances. Some family members chose to allow the person with dementia to continue the same routine in order to feel independent, so they provided support with the task. In these instances, the person with dementia perceived themselves as still feeling relatively independent.

b. Safety issues

Keeping people safe while trying to encourage independence was very important to both the persons with memory loss and their family members. As a result of these discussions, the following techniques were suggested to create a safer environment:

- i. Using technology: "Use of technology- key pads, cell phones." "I try to have a cell phone with me at all times." "Smoke alarms for the home."
- ii. Carry identification: "I wear a dog tag with wife's and son's phone number in case I get lost." "Safe Return Bracelet." "I'm going to get a home alone bracelet."
- iii. Lists: "Create list w/ family to track activities for a day." "Set up schedule that is written." "Use a dry erase board to identify date and schedule of activities and appointments."

c. Staying independent

Remaining as independent as possible for as long as possible was an important theme. Several family members talked about encouraging their relative with dementia to continue to participate in activities that are beneficial and enjoyable. However, many persons with memory loss found it difficult to remain socially active like they used to be: "It's hard to meet people and have a social network. Not working and living with your mom is not normal at such a young age." Other topic areas included:

- i. Interactions with family: Although family members commented on the importance of the person with memory loss remaining independent "Persons with dementia need independence to feel valuable," some felt as if their own independence was compromised as a result of their loved one's condition: "I lost my independence in becoming my mother's caregiver." Others felt closer with their families after diagnosis "I see and talk to my family everyday now, it's great!"
- ii. Feelings of dependence: Some responses from persons with memory loss dealt with becoming increasingly dependent upon their family members as a result of their diagnosis. "I had to give up driving, and need my wife to help finds words to express myself." "Rely on caregiver to oversee activities and to make 'me' feel independent." "Now I limit where my caregiver can go." A family member commented "We've tried to keep as independent as possible, yet the amount of independence has had to be replaced with interdependence and now, even dependence."
- iii. Activities: Participating in certain activities and hobbies helped some persons with memory loss work on remaining independent and social. "I can get on and off the bus and then I tell the driver to take me to the senior center where I can choose what I want to do there, exercise or pool table." Another person mentioned "jigsaw puzzles" as a way to stay mentally active.
- iv. Another theme was the difficulty in balance independence and safety. Many commented on how their family members will encourage them to remain independent at home with certain limitations. One person with memory loss stated he achieves this "By my wife being cautious about my activities." Another stated "I still feel independent at home."

V. Community Resources

Participants were posed the questions: *What sources have you used to get information about services? Were those good or bad experiences? What could be done to help you locate or use services (e.g., by you, by others)?* and *What do you wish was available in your community?* Many people acquired information through the internet and word of mouth. Others found various forums and presentations such as Learning Together I and II educational and resourceful. Several people learned of services through radio, television, pamphlets in doctor's offices, church bulletin boards, and community newsletters. Many of those who were already involved with the Alzheimer's Association expressed satisfaction with the networking that the Association was able to provide. Most of the services discussed seemed to be helpful and beneficial for those involved.

The responses to the above questions centered around three themes: (a) Methods used to acquire services; (b) Challenges with services; (c) Desired services and resources.

a. Methods used to acquire services

Responses indicated that many persons with memory loss and their family members used a variety of different methods in trying to find out about and attempt to utilize services in their communities. The most common themes are indicated below:

- i. Internet: Using the internet to locate services was a common response given by participants. The internet was used to research general information about dementia and memory loss, as well as locating potential services and resources. It was also stated that people used the internet for support services (chat rooms, blogs, online support groups, and message boards).
- ii. Alzheimer's Association: Participants used the Alzheimer's Association services for education, respite, and most commonly, support. "I used Alzheimer's Association to find a doctor." There were many comments made by persons with memory loss and their family members regarding the helpfulness of this organization in providing services as well as providing much needed support. "From Foley, they took us down to the Alzheimer's Association, so we went as early on as possible." Persons were sent to the Alzheimer's Association sometimes from physicians and other medical professions, but most specifically from word of mouth. "The Alzheimer's Association gets an A+ in support and educational experiences."

- iii. Examples of other responses given about methods used to acquire services include: Word of mouth, seminars, senior centers, libraries, media (TV and radio advertising), literature in doctor's offices, sharing of information in support groups, church bulletins and bulletin boards, community newsletters.

b. Challenges with services

The biggest challenge reported from participants is the lack of consistent information available in the community, most surrounding legal and financial help. Some participants found the internet difficult in finding the specific information they were looking for. In terms of support services, several persons with early onset dementia stated it was difficult to participate in a support group with others who were much older than them because the issues are not the same. "Support groups were filled with people 30 years older who couldn't relate to me. It's important to have people my age (50s) to relate to. I didn't want to hear about end-stage disease." "Frustration in finding a place you fit in especially in younger ages, early onset."

c. Desired services and resources

The following suggestions were made in terms of creating new services:

- i. More support groups for persons with dementia only. There are so many for caregivers, but not for persons with dementia.
- ii. Advertising services to more populations to reach out to different types of people. "The Alzheimer's Association needs to advertise themselves to more of the community." "Give local doctors offices literature available to patients regarding Alzheimer's disease." "An Alzheimer's Association info station in each neighborhood, city, and town."
- iii. Need an "Angie's List" of support agencies such as nursing homes, assisted living facilities, and home health agencies. There was an interest in having public agency ratings based on "cleanliness, staff, medical aspects, professionalism, and patient care."
- iv. There is a need for more volunteer opportunities, both for the person with memory loss and as a way to provide respite for family members caring for their loved one. One family member suggested "the Alzheimer's Association could 'employ' volunteers to provide sitters for short periods of care; families would know that they were

appropriately trained.” Another stated “I wish there were volunteer opportunities available, so my spouse could feel more needed. I don’t want ‘babysitting;’ I want active activities that stimulate his thinking and give him a sense of accomplishment.”

VI. Research

Participants were posed the question: *What has been your experience with research that addresses your relationships, how you manage daily, your independence, or your activities (e.g., positive experiences, negative experiences, interest in participating)?* The responses to this question centered around four themes: (a) not aware/had not participated in research; (b) had participated in research; (c) reactions to participating in research; and (d) recommendations related to research.

a. Not aware/had not participated in research

Individuals who made this type of comment often indicated that they were not aware of what research they could participate in. The question was even directly posed: “How do I find out what trials and studies are out there?” Others were simply not interested in participating in any type of research.

b. Had participated in research

Town Hall attendees, family members and persons with memory loss, did indicate participating in some research. The types of research they had participated in included psychosocial research, medical research, and their own personal research.

- i. Psychosocial research studies that were mentioned include an intimacy study, a caregiver study with Foley Elderhealth, a strengths-based intervention study, and a study with the Intergenerational School.
- ii. Medical research that people mentioned included studies involving Vitamin E and fish oil. One individual also noted that he or she had already agreed to donate his or her brain to research.
- iii. Personal research was an unexpected response to this question. Individuals noted techniques and sources they accessed to do their own personal research on Alzheimer’s disease, dementia, and memory loss. Sources most often mentioned for personal research included the public library, the Internet, and health magazines.

c. Reactions to participating in research

Town Hall attendees expressed positive, negative, and neutral reactions to participating in research.

- i. Positive reactions to research were commonly expressed. People noted that the research “gives you new ways to look at things,” and that they “found it helpful.” Comments were also made about how “the more research the better” and that research “validates” and “brings awareness” to the situation.
- ii. There were also negative reactions to participating in research. These comments ranged from people being fearful or skeptical about research to people recounting complications they had while part of a clinical trial. Caregivers specifically mentioned that finding time for research is hard and it is also difficult to get the person with memory loss to the necessary research appointments.
- iii. A few comments from Town Hall attendees were neutral about participating in research. Some simply noted that they “continue to participate in studies” and others indicated that they participated because they “want to help others.”

d. Recommendations related to research

Some participants made comments that really were recommendations about research and the dissemination of research results. Some indicated that they would like to know the results of the studies they had been in, and this is related to other people who felt that “research should be distributed in regular language that is easy for everyone to understand.” One individual expressed that “I would think the doctor would refer us” to possible studies. It was also noted that more research should involve “talking to other family members to get a different perspective from the person with memory loss and the caregiver.”

Open Discussion

The Open Discussion at this Town Hall event occurred as part of the lunch that participants enjoyed. The Open Discussion involved individuals at the tables extending the conversations that began during the structured discussion. Because the Open Discussion was more informal, the comments made were not necessarily recorded by facilitators at the tables nor were the comments captured by the video camera and microphone.

Evaluation and Feedback

All participants at the Town Hall Meeting were asked to evaluate the meeting and provide additional comments. Ninety-seven of the 180 participants completed the evaluation and responded to the following five questions:

Q1. Overall, how satisfied were you with this meeting?

- 93.7% of respondents said that overall they were *very satisfied* with the meeting
- 6.3% said they were *somewhat satisfied*

Q2. Was this meeting a good use of your time?

- 99% of participants said that *yes* the meeting was a good use of time
- the remaining 1% said it was a *somewhat* good use of time

Q3. Were there things that are most important to you discussed today?

- 80% said that *yes* the things most important to them were discussed
- 18.9% responded *somewhat*
- 1.1% said that *no*, the things most important to them were not discussed

Q4. Did you have sufficient opportunity to participate during the meeting?

- Participants generally felt that *yes* they had a sufficient opportunity to participate during the meeting (80%)
- 8.4% responded *somewhat*
- 1.1% said that *no*, they did not have a sufficient opportunity

Q5. Would you like to get more involved with the Alzheimer's Association?

- 62.1% said *yes*
- 31% said *maybe*
- 6.9% said *no*

Two additional open-ended items were asked as part of the evaluation. The first item asked participants for *Comments about today's meeting* and the second item asked participants to share *Comments about how the Alzheimer's Association can help you*.

Comments about today's meeting centered around 7 areas (in order from most common theme to least common theme): (a) information provided at the meeting; (b) social/supportive atmosphere; (c) timing/organization of meeting;

(d) general comments; (e) potential future meeting; (f) moderators/staff; and (g) additional knowledge.

a. Information provided at the meeting

Participants offered positive comments about the information shared at the Town Hall. Two examples are:

- *"This was a wonderful way to hear and see and feel what resources there are available. Thank you."*
- *"I came for information and I got more than I expected. Thank you and God bless."*

b. Social/supportive atmosphere

Several positive comments were also made about how supportive and social the atmosphere was at the event.

- *"I learned I wasn't the only one with the problem. I thank you for the knowledge."*
- *"Reassurance knowing I and my family are not alone in the road of dementia. Such inspiring people sharing their experience and strategies."*

c. Timing/organization of meeting

Participants offered some positive reactions but also some points for improving the timing and organization of the event. Two positive comments were:

- *"very well organized. The meeting flow was excellent. The 'open mike' was helpful."*
- *"Well planned! Timing was excellent opportunity for responding/for asking questions/ to comment."*

Some constructive ideas regarding the organization of the event were:

- *"It was difficult to control the length of the comments."*
- *"I felt that the discussions we had at our table led by the facilitator were more meaningful than the person who spoke on the floor. I would have liked the discussions were longer."*

d. General comments

General comments about the event were also shared by the participants:

- *"Excellent!"*
- *"Glad to be part of this"*
- *"I think this was a good gathering. It was hard to hear all the pain in the room, but I think it all helped."*

e. Potential future meeting

Participants offered encouragement about the potential for more meetings in the future:

- *"Looking forward to more!"*
- *"Would like to come to future meetings sponsored by the Alzheimer's Association"*

f. Moderators/staff

Positive comments were made about the staff and table moderators at the Town Hall:

- *"Nice table-moderator, recorder, family"*
- *"Staff was well-informed and very helpful"*

g. Additional knowledge

Additional thoughts and recommendations related to the Town Hall were shared by participants:

- *"Excellent for early stage. Need more info for late stage Alz"*
- *"Put this info in the Phone Book and on CD"*

There were several *Comments about how the Alzheimer's Association can help you*, and these centered around 3 primary areas (in order from most common theme to least common theme): (a) social support and resources; (b) already satisfied with the Alzheimer's Association; and (c) medical recommendations.

a. Social support and resources

Most of the comments for this item were related to social support and resources. Many of the comments were specific recommendations or needs of families and persons with dementia:

- *"We need specific help in weekend companionship!!!"*
- *"Do an Angie's list of Home care organizations."*
- *"It would be nice to have a published book with all information combined in one book to keep people from searching all over the place for information (e.g., Rated Nursing Homes, Safety Devices, Support groups, Adult day cares)."*
- *"Have a list of support organizations available for caregivers."*
- *"Every day to support me on this journey with my loved one"*

b. Already satisfied with the Alzheimer's Association

Some participants expressed satisfaction with the help that they already receive from the Alzheimer's Association:

- *"Thanks to them (Alzheimer's group) I have found something that I want to be involved in. Thank You."*
- *"They are the best, I could ask of nothing more from them, I know they will always be there for all of us, and hope we will always be there for them."*

c. Medical recommendations

Those making medical recommendations had specific ideas of how the Alzheimer's Association could be helpful:

- *"Legislation to allow doctors and other healthcare professionals to talk with family members/ caregivers about their loved one's Alzheimer's disease. Get more information out about resources available."*
- *"Make recommendations on good doctors that specialize in Alzheimer's disease care that also have open practice."*
- *"[It can help] to seek members and physicians who are involved and helpful."*
- *"Good suggestion- something-an ID to let medical personnel know they should include the family members in the diagnosis and advice."*