



# **Voices of Alzheimer's Disease**

**A summary report  
on the nationwide  
town hall meetings  
for people with early  
stage dementia**

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**Voices of Alzheimer’s Disease:**  
**A Summary Report on the Nationwide Town Hall Meetings for**  
**People with Early Stage Dementia**

Released August 2008

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# Acknowledgements

*The Alzheimer's Association extends its sincere gratitude to the more than 300 people with early-stage Alzheimer's disease and dementia who participated in this nationwide discussion. Your insights and perspectives shed light on a needed new direction, and together we will continue the fight to increase the help available to everyone living with Alzheimer's and the hope of a world without Alzheimer's.*

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# *Introduction*

According to the *2008 Alzheimer's Disease Facts and Figures*, recently released by the Alzheimer's Association, an estimated 5.2 million people in the United States presently have Alzheimer's disease, with projections indicating growth to as many as 16 million by mid-century. Thus, the importance of better understanding the experience of those with Alzheimer's disease is paramount to developing more effective treatment strategies, offering effective care and support programs, and learning how to better enhance quality of life in order to meet the need present today and prepare for the impending wave of people that will be affected.

Historically, the focus of the Alzheimer's field has centered on care strategies for people in the middle and late stages of the disease. First-hand knowledge of the experience of lay and professional caregivers of those with Alzheimer's has been available, but there has been a lack of insight into the true experience and perspectives of people actually diagnosed with the disease. Over the last decade, new information has emerged focusing on the person in the early stages of dementia. This information includes strategies for care partnerships, early stage support group development and improved awareness of the unique issues faced by those with early stage dementia.

Still, with as many as half of those with Alzheimer's in the early stages, there is a great need for increased understanding of the experience and ways to appropriately engage people with the disease directly. This is true today, and is likely to become increasingly so over time. As the life expectancy in the United States continues to rise and the baby boomer generation begins to retire, the impact of Alzheimer's stands to increase as well. However, it is expected that increasing awareness of the disease and its early signs, along with improvements in diagnostic technologies, will result in earlier detection, and it is hoped that disease-modifying treatments developed in coming years will arrest the progression of the disease. Thus, over the next few decades, a growing population of people with Alzheimer's disease will be identified sooner and remain in the early stages longer. As this occurs, the proportion of people with early-stage Alzheimer's relative to those in later stages will likely increase. This change will dramatically alter the present landscape of the disease.

People in the early stage of Alzheimer's have a unique opportunity, prior to the truly debilitating effects of the disease, to play an active role in their own decision making and to participate in planning their experience with the disease. As this report will demonstrate, those with early-stage Alzheimer's seek to be defined not by the memory loss and functional decline they have experienced, but rather by their remaining abilities. Increasingly over the past decade, the Alzheimer's Association has seen more people with early stage coming forward to demand a different experience. It is essential that the Association, along with the field of Alzheimer's professionals and researchers, better understand those with early-stage Alzheimer's and prepare to respond.

# *Early Stage Town Hall Meetings: Program Design and Participation*

## **Origin of the Early Stage Town Hall Meetings**

In recognition of the changing landscape of Alzheimer's disease, with a growing constituency of people in the early stages, the Alzheimer's Association launched its national Early Stage Initiative in 2006. The cornerstone of this Initiative is an advisory group of people with early-stage Alzheimer's that serve as spokespersons, advocates and advisors to the Association, offering first-hand insight into the experience of a person with Alzheimer's.

During the first year of the Initiative, members of the Early Stage Advisory Group clearly indicated that it was important not only to listen to them as representatives of people with the disease, but that the experiences and perspectives of those nationwide would be equally insightful, suggesting a need to cast the net much wider to capture as much input as possible. Therefore, we explored ways in which to facilitate an active dialog directly among those with Alzheimer's nationwide.

Ultimately, the Alzheimer's Association decided to host a series of early stage town hall meetings around the country to give voice to people with early-stage Alzheimer's, allowing us to listen and learn about their experiences and perspectives on the disease. This series of town hall meetings stands as the first-ever nationwide discussion about Alzheimer's disease by people with Alzheimer's disease.

## **Hosting the Meetings**

Between July 2007 and May 2008, the Alzheimer's Association hosted four regional meetings, launched an online "Virtual Town Hall," and Association chapters coordinated local town hall discussions in communities around the country. The four regional meetings, coordinated by the National Office with the support of a host chapter, took place in:

- Oakland, CA: July 28, 2007
- Chicago, IL: August 27, 2007
- Spartanburg, SC: December 1, 2007
- Washington, DC: May 12, 2008

Each of these meetings, along with the local meetings, used a common agenda (see example in Appendix 1) to elicit feedback from participants with early-stage Alzheimer's. Efforts were made in each meeting to encourage any present caregivers or professionals to listen, rather than contributing their comments. The purpose was to hear from people with Alzheimer's disease and dementia.

Based on emerging evidence in the field, guidance from the Association's national advisory group of people with early stage dementia and discussions by the analytical team, three general topic areas were identified for discussion. These were: 1) Interactions with the medical community; 2) Changes in daily life; and 3) Engaging community resources. A structured

discussion led the participants through sharing their experiences and perspectives on each of these topics, with key discussion questions to prompt input in eight specific sub-topics:

1. Diagnosis
2. Available treatments and medicines
3. Participation in research
4. Loss of independence / coping with changes in function
5. Changes in roles and relationships (personal and professional)
6. Safety issues (driving, wandering and home safety)
7. Care and support services
8. Meaningful activities and social opportunities

Based on the high interest expressed during the first and second meetings in Oakland and Chicago, and also given the upcoming election cycle, a decision was made to add a discussion topic of *engaging the fight against the disease* with specific sub-topics of *meaningful advocacy activities* and *involvement in public awareness*. The Spartanburg and Washington Town Halls included these advocacy-related discussions.

After more than two hours of structured discussion around the listed topics, each meeting then included at least 50 minutes of open discussion, in which participants could share thoughts on any topic. Overall, every meeting included a vibrant and lively discussion with many relevant and interesting comments, questions and suggestions provided directly by people with early-stage dementia.

In addition to the in-person meetings, an interactive, online Virtual Town Hall was launched in August 2007. The Virtual Town Hall (which is still available at <http://www.alz.org/townhall>), offers people with early-stage Alzheimer's the opportunity to participate in this nationwide discussion, even if they are unable to attend a live meeting. The discussion topics and questions are the same, and both comments and video clips from earlier Town Hall meetings are available for viewing and consideration. This format further expanded the opportunity to engage people with dementia throughout the nation, and even, throughout the world.

## Meeting Participants

Between July 2007 and May 2008, a total of 301 people with early-stage Alzheimer's or dementia participated in the nationwide discussion. This included 259 early-stage participants present at the live meetings and 42 contributors to the Virtual Town Hall. Including caregivers and professionals, almost 800 people participated in the process, either as active early-stage contributors or as interested observers.

One point worth noting about the Town Hall participants is that there was a large contingent of younger people with early-stage Alzheimer's, or early-onset Alzheimer's. In fact, in the Virtual Town Hall, 57 percent of contributors reported having been diagnosed under the age of 65. Because of the high involvement of individuals with early onset, who comprise only 10 percent of people with Alzheimer's, this unique perspective is very strongly represented in this report. In nearly every section, specific early-onset related themes are presented and explored, alongside the general experience and perspectives provided by people with early-stage Alzheimer's, irrespective of age.

<b>Venue</b>	<b>Number of Attendees</b>	<b>Attendees with Early-Stage Alzheimer's or Dementia</b>
<b>Oakland, CA</b>	194	69
<b>Chicago, IL</b>	105	46
<b>Spartanburg, SC</b>	125	45
<b>Washington, DC</b>	267	99
<b>Virtual Town Hall*</b>	101	42
<b>Total</b>	792	301

\*Contributors as of May 2008

## **Analysis of Program Data**

As one would expect from more than twelve hours of discussion, with greater than three hundred people living with dementia, a rich set of data was gathered to provide insight directly into the experience and perspectives of the community of people diagnosed with Alzheimer's disease and dementia. This qualitative information generated a range of themes and suggestions, providing a window into the experience of Alzheimer's disease.

One should note that while qualitative data provides an in-depth understanding of the contributors' perspectives and sheds light on the experience of early-stage Alzheimer's, it would be misguided to directly generalize individual statements or concepts as reflective of the true view of the estimated 2.6 million people with early-stage Alzheimer's. Likewise, unlike a quantitative analysis, the number of individuals participating is not as relevant to interpreting this data as is consideration of the themes that emerged in the discussion and the common perspectives that were shared.

Data was collected through audio recordings of each meeting, with direct transcription, along with reproduction of comments received in the Virtual Town Hall. An analytical team including Association staff and an external early-stage subject matter expert was convened to review the data, along with an external qualitative analyst. The analytical team attended Town Hall Meetings and reviewed all data in detail, with ongoing discussion to consider themes and major findings. The external qualitative analyst conducted an independent thematic analysis of the transcripts, providing a full report. Final interpretation was conducted by synthesizing the discussions of the analytical team with the report of the external analyst to prepare this summary report, completed August 2008. In an effort to accurately capture the true voice of people with Alzheimer's and dementia, quotes from the town hall meetings play an integral role in the report. In some cases, quotes have been edited slightly to enhance readability without affecting meaning.



# *In Their Own Words*

The central purpose of the Early Stage Town Hall meetings was to provide opportunities for discussion of early stage issues and specifically to hear directly from people with Alzheimer's disease about their personal experiences and perspectives on the meaning of the disease in their lives. This goal was certainly achieved. In each of the meetings, as well as through the Virtual Town Hall, people with early-stage Alzheimer's and dementia stepped forward and offered a window into their lives, sharing their views on how they would like to live and on broader opportunities to support them in this endeavor.

This discussion covered many different topics and views, spanning the first experiences of people with the disease and the reaction of those around them, interactions with the medical community, changes taking place in independence and ways in which to accommodate these changes. Further, the people that participated offered a perspective on how to engage and empower people in the early stages, by reducing stigma, improving relationships, and maintaining independence for as long as possible, enabling them to remain vibrant and contributing members of their respective communities.

This section of the report relays the experiences and perspectives heard in the Town Hall Meetings. While it outlines general themes that emerged from the meetings across a range of topics, it primarily includes quotes from the participants. Each quote is a statement made by a person with Alzheimer's or dementia reflective of concepts identified in the full analysis. As in the meetings, the content swiftly moves from subject to subject, but overall paints a picture of an experience, and shapes a vision for action and active involvement.

## **Public Perception and the Stigma of Alzheimer's disease**

A theme that extended to almost every area of focus illuminated during the Town Hall Meetings was a reported stigma associated with Alzheimer's and the effects on those living with the disease. The impact of stigma was very present in discussion about symptoms, recognition and diagnosis. Many people reported a hesitation in admitting they had Alzheimer's disease for fear of negative public perceptions about the disease and its potential for causing social isolation. The potential stigma had an effect in the other direction as well, inspiring some people to want everyone to know they were living with Alzheimer's disease. So, while some felt like hiding their condition, others felt a sense of relief to be able to share what they were experiencing.

- “When people say ‘dementia’ or ‘Alzheimer’s,’ everybody thinks you’re going to die.”
- The general public’s attitude toward Alzheimer’s in some instances is not very nice. In fact, excuse my expression, but I’d have to say it sucks. But it does because we *let* it.”
- “There is a stigma that goes along with the disease. Many people are worried about sharing the fact openly that they have this disease because of the negative stigma. I heard someone whisper the other day, ‘My father has Alzheimer’s.’ I just gave him a big hug and said, ‘You don’t have to whisper – shout it out loud.’”

- “I’m not ashamed of having Alzheimer’s. All my neighbors are aware I have a problem and there’s no ridicule, no stigma, and so I wish we would get it out of our minds that we’ve done something; that we need to go under the table and hide.”
- “I’ve been very open with my friends. I think it’s important that we educate people to the extent we can.”

## **Experiencing Symptoms and Gaining Understanding**

### **Denial, Anger and Acceptance**

Many people with early-stage Alzheimer’s reported that when they were initially confronted with a diagnosis, they attempted to deny the symptoms they experienced and what they needed to do to address them. Often, participants shared that they had tried to accommodate or hide the challenges they were experiencing from loved ones and co-workers.

- “I knew there was something wrong. I was in denial, but I still knew it.”
- “I used to work for a large corporation and I managed to cover up my problem for years. I got by with a number of lying devices for three or four years.”
- “One of the dimensions of denial is that this disease is a lot more visible from the outside than it is from the inside. My wife and family decided I needed to get checked.”

Denial was reported to affect one’s interest in getting evaluated, but also persisted even after a diagnosis. Some people were very angry and grieving over the new knowledge of their condition. People were reluctant to admit to others what they were experiencing or that they had Alzheimer’s. Yet there was often a sense of relief when they were able to admit their condition to themselves and others. People reported that acceptance of their condition resulted in a better ability to cope moving forward. It was viewed as liberating to let the denial go. For some, the town hall forum provided the safe haven required to finally reach that state of acceptance.

- “I started out very, very angry. I did go through that extreme anger and the ‘Why me?’”
- “People should have an opportunity to grieve. There’s about nine steps to grief. We need to go through all of them. We’ve been angry. Why is this happening to us? These are the so-called golden years – what happened to the gold?”
- “I’m better able to say to people now that I have Alzheimer’s. It was really hard to say the word, ‘I have Alzheimer’s,’ to say that sentence, but I feel easier about it and I’m better able to cope now.”
- “What I’m going to do here for the first time is publicly say that I have full-blown Alzheimer’s disease.”

Even after the person with the disease has come to terms, denial and a general lack of understanding was still present among family and friends. Like the person receiving the diagnosis, denial was also reported as something that persisted well after the diagnosis for those around them. This was particularly true for people with early-onset Alzheimer's because they were diagnosed at a point in time when it was truly unexpected.

- “My husband and children are in complete denial, so that’s very difficult. They know I have it, but when I do something out of the ordinary, they can’t understand why I can’t get it the first time and they start getting upset with me. And I can’t help it.”
- “I encountered family and friends who were reluctant at first to accept my diagnosis, and it meant dealing with their denial. It would be helpful for them to accept it rather than pretend it doesn’t exist.”
- “Friends had a difficult time when I was first diagnosed, and I realized it was because they just didn’t know enough about the disease, and I felt it was important that I speak up about it.”
- “I’ve had people in my life that when I said I’ve been diagnosed with Alzheimer’s, they stepped back. Some of them accused me of making a bad joke. Some of them said, ‘You can’t have that – you’re not that old.’”

## **A Different Experience: Receiving an Early Onset Diagnosis**

For younger people with Alzheimer's disease, or those with “early-onset Alzheimer's,” diagnosed under the age of 65, participants identified unique issues and concerns. Largely the differences in terms of experiencing symptoms and recognizing the disease dealt with the fact that they were at a different point in the life course, and were often still working. Many of the symptoms they experienced were related to job performance, noticing something was wrong because they were unable to function at a high level in their respective roles at work.

- “I was selling cars. I’ve been a salesman all my life. I’d introduce myself to people and they’d tell me their names and I’d walk away and couldn’t remember their names. During the process of the loan, I would not be able to pull out some of the words I wanted to use – I’d have to stop and think.”
- “I did not sense I was having difficulty and my wife didn’t either. Some people I worked with started noticing I did things that weren’t quite what they thought I would normally do. They went to a supervisor. Fortunately, she took the path of calling me in and telling me what she’d heard. It was a blow.”
- “I had just started a new profession. One day in front of a whole crowd of people, I asked a question of my supervisor. I said, ‘Are you sure?’ She said, ‘Betty, what in the hell’s wrong with you? You’ve asked me that question four times!’ The next day I was in a neurologist’s office.”

Denial was also quite pronounced for those in early onset because of the perception of Alzheimer's as "an old person's disease." As will be highlighted in the next section, this extended not only to the person with the disease and their family, but also to denial on the part of the medical community and physicians, resulting in diagnostic challenges.

## **Desire for Early Detection**

Despite the stigma and uncertainty, participants widely acknowledged that it was beneficial to recognize signs of the disease as early as possible. The diagnostic process was described as challenging, and accepting one's condition was difficult, but once the process was complete, people reported many benefits and encouraged others to seek a diagnosis if they were concerned or experiencing signs. In spite of the frustrations they experienced, the participants believed in the importance of early diagnosis and awareness of the disease.

- "Early diagnosis is vital. It's made all the difference in the world to my life. It gives us a purpose and allows us time to get our house in order."
- "If I didn't have a great psychologist who wasn't looking at my age but the symptoms, someone still may be trying to shove depression meds at me. An early diagnosis is the key to a long life."
- "Everyone should insist on early screening via the mental mini-test or some equivalent. We need to begin attacking the disease at its earliest stages."

## **Getting a Diagnosis and Interacting with the Medical Community**

### **The Diagnostic Process**

One of the most difficult and emotionally charged issues discussed at the meetings was the diagnostic experience. The process of receiving a diagnosis of Alzheimer's disease or dementia was described by participants as prolonged, difficult and often extremely frustrating. Quite a few participants noted that they received their diagnosis in a circuitous manner, describing well the impact of a differential diagnosis on the individual in terms of ongoing uncertainty and fears. While it is important to note the clinical challenges of diagnosing Alzheimer's, as well as the high diagnostic accuracy achieved by trained clinicians, the participants provided great insight into their experience as people with the disease that may be useful in improving the process.

- "My diagnosis took eight months. I know people for whom it took two or three years. I've talked to some people who had one test and the doctor told them they had probable Alzheimer's. I went through a battery – neuropsych testing, spinal taps, MRIs, blood work – you name it and I went through it."
- "They found something in an MRI, an arachnoid cyst, so I thought that's what the problem was. The neurologist asked me a bunch of questions about had I ever hit my

head, which I've been knocked out at least twice. I went through psychological tests and everything, and went back in and he said, 'you have Alzheimer's.'"

- "I'm a retired doctor. I think everybody I've talked to that has Alzheimer's has a story to tell about their diagnosis experience. It has to do with the vagueness of the diagnostic skills, and the capability and such of the profession. In this bright age of science, we still don't have a defining way of making a diagnosis early that says 'This is Alzheimer's, and let's cope with it.'"
- "I describe the process as a big pile of rocks on the table and with each test, they remove a rock until the only rock left is the one labeled 'Alzheimer's.' The difficult part as the patient was that I really didn't know how many rocks were on the table. I didn't know why I was taking another test -- just that I was asked to take another and another and another. Bring the patient into the process a little more and help us understand why we're taking certain tests, where we think we might be headed, and what the next steps are."

Another common concern regarding the diagnostic process was the burden of the tests being administered and the extent to which it drained and in some cases demoralized the people with dementia. Also, as the process unfolded and the burden increased, some reported that the interactions they experienced with the clinicians were less than satisfying in terms of receiving comfort, feeling compassion and general bedside manner.

- "They sent me to this lady who absolutely destroyed me. She brought out four, five, six, seven, eight -- I don't know how many pages of tests and I couldn't do all of them and it got worse and worse because I was just feeling completely debilitated by the way they were handling this."
- "They put me through the whole rigmarole, a four-hour test that I came out of feeling like a total idiot. You come out thinking, 'Where am I? Who am I?'"
- "The test was four hours long and I felt absolutely invaded. I felt so worthless. I felt so hopeless."
- "Healthcare professionals need to take us more seriously and most of all *listen* to our questions and concerns. Don't just shove another pill at us to get us out of the office -- treat us as if we were their mother, father, sister, or brother."

## **Perceptions of Professional Denial**

A few participants felt doctors were subject to denial along with the people with dementia and their families. They believed that doctors or health professionals were missing diagnoses due to their own fears about the disease or because they had a more intense focus on other conditions commonly affecting the elderly. This bias was believed to diminish the clinician's ability to make a proper diagnosis, particularly for younger people. While this experience was true for participants of a variety of ages, it was especially difficult for younger people because Alzheimer's is often not considered as readily as with older adults.

- “Like many, I was diagnosed with stress, depression, hormonal changes, chemical imbalance, and even had a hysterectomy before finally getting the doctors to listen to me. We lost two years that I was progressing and of quality time with my family because doctors wouldn’t give me a diagnosis because of my age. I was 38.”
- “We went to a neurologist and he went through a few simple tests and said, ‘No, he’s fine.’ I went back six months later and told him to check for Alzheimer’s again, and he said, ‘What is it you don’t understand about what I told you the last time? You don’t have it.’”
- “I’d never seen a doctor so disappointed to tell someone they *didn’t* have a brain tumor.”

## After the Diagnosis

Participants expressed many views on how they feel the follow-up to their diagnosis could have been improved. They relayed the perception that they were abandoned and became isolated after learning of their condition. They offered various suggestions on how to improve the connections between the recently diagnosed patients and the care community in ways that would extend throughout the course of their experience with Alzheimer’s.

- “When I was diagnosed, the doctor basically gave me my medicine and said, ‘Come back in six months and we’ll talk again.’”
- “My doctor just kind of let me go, because he was of the belief that there was no treatment. He just kind of cut me loose. ‘You have dementia and there’s nothing that can be done. It’s a progressive illness. Goodbye.’”
- “My doctor at the university sent my record and everything to my doctor my clinic, and she never did call me. I had to see her for something else and I asked her about it. ‘Oh, yes, you know...’ and then she sent me off to another doctor. I haven’t seen her since. The next thing I knew I got a letter from the DMV – that’s all there was to it.”
- “We’re taken into the room and he’s being all perky and he says, ‘Oh, you have dementia.’ He closes the folder and walks out the room and leaves me there with my daughter. I literally had to run after him – he was going for his next patient.
- “My experience was that once you’re diagnosed, you’re told, ‘Here’s a prescription for Aricept. I’d like to see you in a year.’ I’ve talked to neurologists who say, ‘Once I find out what’s wrong with you, I feel like I did my job.’ But that’s just the beginning for the treatment model.”
- “I would have appreciated discussing with my doctor ways to delay the progression of the disease beyond taking medication. That didn’t happen. It is up to me to be my own advocate and discover best how I should be taking care of myself. More direction and support from the health professionals would be helpful, but I’m doing it.”

There were also comments about the need for creating a more direct link between a doctor diagnosing Alzheimer's (or a related dementia) and referrals to available community services. Specifically, people recommended that diagnosing doctor direct them to the Alzheimer's Association to make them aware of the support that is available beyond medicines.

- "If there was a way the Alzheimer's Association and physicians could partner up so when you're diagnosed they could say, 'Here's the Aricept and here's a packet of information I think would be really helpful for you,' that would be something I'd recommend."
- "What I would like to see is more of an open path from the doctor's office to the Alzheimer's Association. Once you're diagnosed, they should say, 'You should probably contact the Alzheimer's Association.' It would be better somehow if they provided more information at the doctor's office on where to go from here."
- "What do you do? Do you go to the Yellow Pages? Where do you go? Who can tell you where? Is the caregiver you go to supposed to tell you? What type of information and what facilities do we have to help us?"

## **Treatments and Clinical Trials**

Many respondents praised the various medications they were taking (while acknowledging some experimentation was necessary, and some side effects were problematic), because they felt the prescriptions had really helped them live a somewhat normal life. The statements express true appreciation for the improved quality of life and enhanced functioning that they receive from the treatments currently available. Participants described their experience taking medications of various types, and there was considerable excitement at some of the results.

- "I've been taking Aricept for about the last five months, and all of my close friends tell me I'm much better now, so it really seems to be working for me, which is really saving my life."
- "I am so grateful for the clarity I am getting from the medication. I still struggle with short-term memory, but I can function pretty normally on a daily basis. I am so thankful for the research that was done to make this medication for myself and other patients like me who struggle with memory problems."
- "I can tell you that if I did not have the Razadyne and Namenda and the other things I take, I would not be able to stand here today and speak. That means a lot to me, that I have a medication that allows me to continue my life with the disease."
- "I've been on the small Exelon patch for two weeks and I can tell the biggest difference. I can function now. I'm on a lot of boards and I'm very active in the community. I am so much better."

At the same time there is gratitude for the benefits received, there were also questions about what other medications might be available that may be even better. There seemed to be a lack of confidence over whether they were doing everything they could (or even the right things) for treatment, and thus asked many questions about available medications and current research.

People were always on the lookout for something newer, better, more effective, less problematic, and/or less expensive.

- “I would be interested in knowing, is Aricept the best thing to be taking, or are there other things around the corner that are even better?”
- “Last night I read in *Popular Science* an article on Alzheimer’s, and it listed a medication in phase three test. This was said to actually reverse the plaque growth. I was hoping you’d know the name of the stuff.”

There was a great deal of interest not only in learning about the latest research, but also in participating in research trials. In fact, many people reported that they were already participating in research. The desire to do so was multifaceted, but was typically based either on an interest in learning more about their condition and receiving the latest experimental treatments or out of a desire to help future generations.

- “I went because of my experience with the physician, and that I wanted to find something I could help out with, too. I wanted to find out for sure what was wrong with me, and it would help them do the study. I figured it would be a good thing to do for other people, my own kids, whatever – so I did it.”
- “I’m doing it because if it runs in the family, I don’t want my children to have it, so I want to get a cure for it.”

Once interested in participating in a clinical trial, or even when doing so, there was a desire expressed for more information. In some cases, people wanted more information about the trials that were available for them to take part in, while in other cases they struggled to receive sufficient information to make a decision whether to participate. Additionally, people felt they did not receive adequate follow up information and were disappointed the researchers did not share their findings.

- “I’ve had three vaccines now and basically I’m a guinea pig on this. You don’t know what you’re going to face when you get there, but I decided I was willing to take any risk they might throw at me.”
- “My brother and I have taken part in the University Alzheimer’s approach, which was very good, but I’m disappointed. We haven’t heard back from them as far as what their accomplishments were.”

Further, there was a strong sentiment about the different experience of younger people with Alzheimer’s and their being excluded from a trial because of their age. They felt this was unfair, particularly since so many wanted to serve as advocates, and help do something to either lessen the impact of dementia on future generations, or to eliminate it altogether. The early-onset community is calling for a change to research eligibility criteria.

- “I was told I was too young. There’s an age limit – 55, and two years ago it was 65. I’ve been advocating for people to lower the age limit so they can catch it at the earliest



moment. I've been available for many of them, but not many of them have called because of that."

- "I'm not currently participating in a clinical trial. I just turned 50, and my understanding is that people my age are not eligible for Alzheimer's drug clinical trials. The catch-22 in this is that drug companies will often say that the drugs are not FDA-recommended for people in early onset, but the reason they say this is because we were not included in the studies. We could contribute valuable information to them for research purposes."

## **Living with Dementia**

### **Changes in Independence**

Due to the progressive nature of the disease and the variable changes that accompany dementia, learning to live with the condition is a dynamic process. As noted earlier, people often said they had to grieve and go through anger and confusion once they got the diagnosis, but that they then arrived at the realization that it was their choice whether or not to enjoy the time they had left and do something with it. While they often feared the future, they refused to let that defeat the present.

It was clear that there is a strong frustration and fear associated with the disease and the loss of independence, including both immediate or present changes and the anticipation of the changes on the horizon. People also expressed their efforts to maintain their independence and prevent others from disempowering them.

- "I've always been a very independent person, so when I was diagnosed the first thing I thought about was that I was going to have to depend on other people, and that was scary to me."
- "I had a difficult time accepting the diagnosis, as my father and grandfather both had Alzheimer's disease and I knew what it looked like 'down the road.'"
- "The hardest part is being humiliated by being dependent on other people for your care."
- "I am scared. I don't know how long I will be able to work, care for myself, stay at home, and the like. My husband and sons tell me not to worry, they will take care of me – but what a burden will I be?"

At the same time, it is difficult for people to accept the existing or pending loss of independence, because on a day-to-day basis, they do not necessarily feel as if anything is wrong. Rather, they want to acknowledge their own remaining abilities and their desire to remain the people they are, while connecting with others having a similar experience. Still, they acknowledge that Alzheimer's is present and frequently attribute daily missteps to the disease, appropriately and inappropriately.

- “I didn’t know anything was wrong. I didn’t have a clue, and I still don’t feel like it. I don’t feel like it, but I know it’s there and I’ve got to deal with it.”
- “In my town, we have a place called Adult Day Care. Very nice place. But I would like to see some place to go for early stages. I feel like my life is pretty normal and I would like to get to know other people like me
- “My wife and family haven’t let up on me. There are things to do at home and I still have to do them. I have to be careful not to use this as an excuse, because I forgot her birthday and I tried to use the Alzheimer’s. It didn’t work.”
- “If I say something, sometimes it gets pinned on Alzheimer’s, whereas someone else in the family can say the same thing. I don’t feel that way. I feel like I’m just going along like everybody else, but then some people point it out to me that it’s Alzheimer’s.”

The anticipation of dependence was very frustrating. A very common concern, often described as a proxy for general worries about loss of independence was the issue of driving. Some had made allowances for their limitations (e.g. only driving around their gated community), some had given up driving completely, and some proudly and defiantly continued to drive, with the claim that their disease had not impaired their driving yet. The accuracy of this assessment is another issue altogether.

One of the greatest debates and issues for a person with dementia is the point at which one must stop driving and the impact of this decision. For those who reported that they had not stopped driving, there was great anxiety and even guilt about when and how to make the right decision.

- “I don’t feel any different many, many times during a day. The one thing that will really bother me is when I can’t drive, because I’ve been a car nut all my life, so that will be a real problem.”
- “I never had any problems driving; the police haven’t stopped me even one time. I don’t have the mind I had when I was younger, but it’s not to the point I need help.”
- “We got involved in a support group and the immediate message was, ‘You should stop driving immediately.’ My answer was, ‘If I had anything else, you would be looking for a way to *enable* me.’ I should let my capabilities drive my activities, not just take an arbitrary limit and throw out one of the things we do that are actually useful. I took an intensive, three-hour driving evaluation and got a perfect score.”
- “I still drive all over the United States. I get yelled at all the time for doing that. I’m just not willing to give up yet.”

Some reported that they had already stopped driving. For these individuals, there was generally a theme of being able to identify ways to accommodate the change.

- “I was really very annoyed when they told me I shouldn’t drive when in fact, I felt I could do it.”

- “I used to worry about when I couldn’t drive any more, but my wife is nice enough to take me around all over the place, so I can’t say it’s really impacted me a whole lot.”
- “It was very difficult giving up things such as a car when I’m still working. It’s fifteen miles, so when you can’t drive it poses a bit of a problem. Without my wife taking me to work in the morning and a driver taking me home in the afternoon, I would be pretty much stuck in the house every day.”
- “I’ve given up driving, but my wife provided me with a golf cart. I live in a gated community, so I’m able to tool around at two miles an hour in my golf cart.”

## **Staying Active and Coping with Changes**

Another common concern expressed by participants was that their condition separates them from other people and the “normal” lifestyles other people their age are experiencing. Their relative independence and sense of normality is affected by the disease. Again, this was particularly true for younger people.

- “Most of my friends are working and I can’t work any more, so that’s a challenge for me. I have to find ways to keep myself busy and active. It’s hard because I’m a social person and I like to be around other people, and because most of my friends are working, I don’t have that opportunity.”
- “I was a registered nurse in a hospital for the last twenty years with hardly any time off. I don’t know what to do with all this time on my hands. What do other people like me do with all of their time?”

Participants shared that people with Alzheimer’s know they will have to give some things up, but don’t want to have things taken away from them until it is absolutely necessary. They wanted to be as involved as much as they could in daily life, friendships and decisions. It was a difficult balance between the challenges they were experienced and a desire for independence – attempting to meet their own needs while maximizing remaining abilities.

The solution they described was that it is not appropriate to just take away everything from someone with Alzheimer’s. They still need to remain involved, remaining as active, and responsible for as long as possible.

- “I am not incapacitated and I don’t want to be treated as though I can’t be trusted to do things. It’s a balancing act that, for me, is constantly being navigated.”
- “I still have some capacity left, but my wife does not give me space to breathe. She thinks she knows best, and my opinion is disregarded. She is away today, and I looked forward to a day of rest and peace. However, she arranged for my daughter to ‘drop in’ as if I couldn’t survive on my own for a short while.”

- “My family can help me cope by maintaining a normal relationship with me and helping me maintain normal connections to others. They can also help by knowing that I still have many skills and abilities left – I’m still here!”
- “Don’t, through the kindness and goodness of your heart, take us out of the decision-making, because it’s use-it-or-lose-it. When you take something away from a person, they’ll never get it back.”
- “I am Sylvia. I was Sylvia before I was diagnosed, and I am still Sylvia after being diagnosed. I’m still the same person – treat me the same way. Talk to me the same way. Include me in the conversation as you would before.”

They also said they needed to continue to live life, and that this disease had taught them to value what’s really important and dismiss what’s not. They wanted to focus on what they could do, not what they couldn’t. They wanted to stay physically active. They also had to face the issue of what they really wanted out of life. Some people made a point of saying that they are trying to stay as active as possible. They struggle sometimes, but they don’t want to go down without a fight.

- “I like to say that I mourn the things I can’t do, but I celebrate the things I still can.”
- “You cannot survive for very long with a downer attitude about Alzheimer’s. You just can’t. It eats you. We’ve got two choices. We can either go off in a corner and cry, or we can laugh at this idiotic disease that’s trying to eat us up.”
- “We’ve tried to be active physically. We’ve gone on three-week trips to New Zealand and we’re going on a trip to Ireland in October. We’re going to try to do things that are good and happy.”
- “Exercise and mental exercise are very important. Reading is very important. Doing activities that now have to be written down and checked off is very important.”

There were numerous discussions about ways in which to effectively cope with the changes taking place. People commented on how they had learned to forge a new life in coping with this diagnosis. These people with early stage, were clearly living with Alzheimer’s, not dying from it. For some people, the key was trying to do the same things they did before the diagnosis, but figuring out a new way of doing them.

- “The thing you have to remember for yourself is that I’m not giving up on my life -- I’m building a new life. I didn’t want to give up my old life, because I loved nursing. But what I do now is paint and I speak and let people know about my disease and I let people know there are other ways to live.”
- “I think I’ve adjusted pretty well, and it’s not as terrible as it sounds, because I can still do the *New York Times* crossword puzzle. To me, life is really quite good. I mean, there are things I can’t do, but they don’t matter any more. I can concentrate on people and books I like to read and the music I like to play or listen to.”

- “I try to do the same things I used to be able to do – we just have to find a different way to do them sometimes. I use the analogy that if you broke your leg, you’d have to figure out how to walk with crutches or get around in a wheelchair.”
- “We have a daily plan. I can’t remember things. If I don’t have my daily plan, I get one or two things done and I’m happy, but I get in trouble when my wife comes home.”

There were numerous participants that discussed the importance of physical activity in dealing with this disease.

- “I’m physically active -- I play 18 holes of golf a week. I’ve got three or four buddies that like to play competitive badminton so we go out to the college and whack it around for two or three hours.”
- “I’m using my bicycle more often. It does really make a difference to me, and besides just getting your exercise and feeling good, it’s a good way to get with other people and go on bike rides together and things like that.”
- “I find that exercise helps me feel positive about my future, and keeps me feeling athletic and strong.”
- “Diet and exercise has been critical in my ability to cope with Alzheimer’s.”
- “Keep yourself physically fit as best you can and get on the treadmill or anything else that will help you, because I think it will be good in the long run.”

For still others, humor is very important in dealing with this disease and its impact.

- “I know how uncomfortable I would feel if I knew one of my friends had Alzheimer’s, and what I would say to him. I decided to defuse the situation. If they ask me how I am feeling, I say, ‘Great – I haven’t lost my keys all day.’ I wanted to keep the situation humorous. It’s worked very well.”
- “The greatest gift my mother gave me was the gift of laughing. I’d just like to tell everyone how much laughter is most important. It is the most healing thing you can do for yourself.”
- “I will meet this challenge with humor at the things I do and say. To give in and lose is not an option.”

The overwhelming sentiment was that people are not willing to be disempowered or allow their contributions or activities to be diminished in any way. There is a strong desire on the part of people in early stage to remain active, vibrant and positive members of their community. Furthermore, while some people not only described what abilities they retain despite to the disease, others shared their perspective on what they have gained from their experience with the

disease. They indicated that this time brought them a new view of life and a new appreciation of the abilities they still have.

- “I would trade it to go back and not have Alzheimer’s, but at the same time I’ve learned so much from this disease and bearing it. I have a different understanding of the world and the people around me, and a more intense joy of life than I had before.”
- “We decided we wanted to fight. I didn’t want to just sit around. A lot of the things you once think are important to do, you don’t have to do any more because you have things that are more important.”
- “I want to tell you how blessed I feel that I have this. Really I am. I never was mad. I feel so blessed because the simple fact is, I can go in there and fight for us. It is hard, but I feel very blessed we can help others.”

## **Changes in Relationships**

There was a recognition that dealing with this issue involves the dyad of both the person with the disease and their care partner equally. People with early-stage dementia were frustrated by their interactions with others who were now afraid of them or treated them like less than the full people they are. At the same time, they noted that they themselves sometimes contributed to the problem by not fully explaining what they wanted or needed from friends and family.

For many, relationships are the biggest frustration. Some people they thought were friends simply stopped seeing them, or started treating them differently. They were excluded from conversations. They were treated as though they were incompetent. While they recognized why this was happening, it still hurt and frustrated them.

In the discussions, it was obvious that relationships change with dementia. For many individuals in the early stage, relationships are their biggest frustration. As noted earlier, some people are in denial, or afraid of the stigma related to the disease and it can have a direct effect on people’s personal relationships.

- “A diagnosis of Alzheimer’s terrifies me. However, my family and friends act as though I have the flu. I’ve sent them sites from the web, pamphlets, books, etc. No one reads them. No one talks to me about my feelings. They only laugh when I tell them I put the milk under the sink instead of in the fridge. I suppose it’s funny, but I don’t feel like laughing.”
- “I always tell people I haven’t lost my mind; I’m not crazy. I’ve only lost some brain cells.”
- “People shy away from you. It’s like a reaction that might be associated with BO. It’s something you can’t help, but really, they don’t want to know and they don’t want to be involved.”

- “People who knew I had this would ask me how I was. Now, that’s a polite thing to do. My reaction at times was, ‘How the hell do you think I am? I’ve just been diagnosed with an incurable, always fatal disease!’ I didn’t say that, but I wanted to.”

One sentiment tied to the change in relationships is that when people develop the disease, it serves as an immediate test of friendships, some of which do not last. Participants shared their strong resentment about friends who made them feel abandoned.

- “When I came down with Alzheimer’s, my friends weren’t my friends any more. They don’t come to talk with me or just to be with me, like I guess they’re frightened that they’re going to catch the same thing.”
- “We have a lot of friends, and we don’t see them very much any more. It’s almost like they expect to see me like they see on TV – a little old man walking around somewhere who has Alzheimer’s. I guess they don’t want to be around people like that.”
- “I have found that people tend to pull away from me when they hear of my diagnosis, or they notice the changes in me. This disease is hard enough to go through with family, but to go it alone is just horrible.”
- “I was a nurse. I don’t see any of the nurses I worked with any more. You’ll know through this disease who your friends are and who your friends aren’t, and that’s who you’ll want around you.”

Another common complaint from participants was that other people often make them feel stupid or like less of a person because of their disease. Also, as the relationships change and people’s interactions are altered, a sense of doubt emerge which can be challenging to overcome and remain positively engaged.

- “People didn’t know how to talk to me even though I was the same person I was five minutes before I told them I had it. They just saw this big A on my forehead. They didn’t look at me as the same person – I was stupid, or couldn’t carry a conversation, or have a single thought of my own, which was very distressing to me.”
- “I think my family could be more forgiving of me when I don’t remember things, instead of saying, ‘I already told you that!’ I don’t forget just to annoy them.”
- “I should never have told some ‘friends’ about the diagnosis. I guess I was looking for some sort of support from them, but they immediately began to distance themselves from me. Whenever it became obvious that they had failed to communicate something to me, I would just hear, ‘You just forgot.’ This memory lingers and still hurts my mind and heart.”
- “Once you have the label of having Alzheimer’s, there’s a subtle kind of loss of credibility that takes place. I was on the board of directors for our homeowner’s association, and when it became public that I have Alzheimer’s, almost anything I brought to the table got put away. It was not direct – it was sort of managed behind the scenes.”

One overpowering feeling among those with early stage was a sense of isolation. They stated that their relationships are changing, their abilities are changing and that regardless of the level of support received, they have the feeling of being alone even when they are not. It was clear from the discussions that people with dementia seek connections and support.

- “Since I am the only person I know who has Alzheimer’s disease, I wish I could talk to other people in my position. I feel like I am the only one who knows what this feels like.”
- “I’m married and I’ve got strong family support, but you’re alone in a way that’s hard to explain. The other night I was watching highlights of Johnny Carson and George Goebel was on there and said, ‘Do you ever feel like you’re in a room full of tuxedos and you’re a brown pair of loafers?’ That hit a little close to home.”

The point was also made that people with early-stage Alzheimer’s need to look at things from the other perspective – that they need to understand people are not intuitive and don’t always know what type of help they may or may not need. There is a recognition that sometimes care partners don’t know when to help and when to back away without being given appropriate feedback from the person with Alzheimer’s.

- “I found I had to tell people what I needed. For a long time I wanted them to read my mind, figure out the problems I was having, and just come to my aid. It’s very difficult to ask for help, but I found that if I didn’t tell them exactly what I needed, I wasn’t going to get through it”
- “Our friends and our families don’t know what we’re thinking and how things change for us, so we do have to educate them. I have a difficult time with noise. Going out to dinner causes a problem for me because restaurants are very loud, so I have to tell my friends that. They’re still willing to go to lunch with me, but at 11:15 instead of noon. For me it’s a big change, but my friends would never think about it so we have to help educate our family and our communities as to what we can and cannot deal with.”
- “One of the major challenges for me was to help them to speak differently to me. My husband said to me, ‘Boy, I can’t wait until Thursday, can you?’ and it’s like, ‘What’s Thursday?’ You don’t have a clue. I’ve had to teach them to say, ‘I’m looking forward to Thursday when we’ll see the Joneses – won’t that be nice?’
- “We can’t multi-task. My wife will interrupt me in the middle of something. I’ll stop what I’m doing and she’ll tell me something. I’ll write it down and I’ll say, ‘Remember, you’re not supposed to do that.’ I can’t get back to whatever it was I was doing so I’ll get up and go do something else.”
- “If you and I are talking and you try to help me finish a sentence, I’m now dead in the water because I’ve had to stop and listen to you. You don’t intend to, you’re trying to help, but as you interrupt me, it just stops my thought.”



Particularly for people with early-onset Alzheimer's, another challenge faced due to changing relationships is the impact at work and the changing interactions with colleagues. It was clear that some employers had been very gracious, while others had not handled the situation well.

- “After learning my diagnosis, my employer sent me a letter telling me I was no longer able to perform the duties of my job. I thought there might have been a better way to utilize my skills than to dismiss me at the first opportunity.”
- “I helped write the operating system for the world's first cryogenic reciprocal super computer, and then the Alzheimer's kicked in. I said, ‘Well, I'm not proud, I'll go to work at Home Depot.’ And they put me in the bloody carpet department, and there's fifty thousand choices of carpet at Home Depot, so that job didn't last long.”
- “When I was working in the non-profit organization I was in, they had changed their pattern of working with me very subtly, taking away things, restricting what I got into, and so on. They knew two years before I did that something was wrong.”

## **Coming to Terms and Planning Ahead**

Learning to live with Alzheimer's disease also includes the need to come to terms with the diagnosis one has received, set realistic expectations and determine where to go from here. One of the questions people with early stage asked of themselves was what they want out of life now that it has taken an unexpected turn. Recognizing what the future holds, learning to adapt and adjust, making decisions about the future and setting some goals was found to be very helpful.

- “My whole life was my work, but that suddenly stopped. My friends would ask me, ‘What do you want?’ My answer is, what I want is not too different than what you want. I want to go to lunch and talk about Alzheimer's, but then I want to talk about sports. I want to live the same life I lived before.”
- “We have a choice. We get dealt a blow with Alzheimer's and that's a huge blow. We have choices to make in life – you can choose to grieve or you can choose to celebrate. For me, I've decided that maybe this is the best time of life. I don't have to work any more – I can have fun.”
- “What I realized is you cannot dwell too long on what you can't do any more. It is a new life -- how do I begin to take my new life on?”

Closely related to early-onset dementia is the loss of income and the need to plan for the financial future. The expenses associated with the disease are impactful for those in retirement, but participants felt that retired people have already had the opportunity to build up their reserves. People with early-onset not only have the added expenses, but they never had the chance to fulfill their retirement savings plan. Thus the importance of financial and life planning was very present on minds of participants during the discussions.

- “If you're still working, it disrupts your life faster than a person who's retired.”

- “There is no difference in Alzheimer’s regardless of our age. A lot of the difference is that we lose our jobs and our ability to continue putting money into a bank account for our retirement. We’ve lost our working days and sometimes we’ve lost our families because of this disease.”
- “We’re facing the future with real economic, spiritual, and medical consequences that are unknown. In preparation, we’ve moved to a smaller home. We’ve altered our physical and economic situation so we can look to the long-term future. The people in denial are really just setting themselves up for something terrible.”

## **Accessing Community Services and Staying Engaged**

### **Care and Support Services**

It was widely expressed that general support and specific support services are very important to enhance quality of life and improve connections with others. Some support came from friends or family members, but often it was in the form of support groups and programs delivered by community agencies such as the Alzheimer’s Association.

There was again recognition of the need to take responsibility for their own care and their own needs. The people with early stage explained that they learned they cannot just wait for others to help them – they must go out and help themselves to the best of their ability. In particular, they wanted to ensure their involvement in the planning and decision making process for developing effective programs and services. Thus, they readily lent their voice to share perspectives on what will be most effective. As in personal relationships, they realized the need to tell others what they want and need, but they also want to be asked. The point was made that they do want to remain responsible for asserting their needs and wants in terms of services, but also in life in general.

- “I think so many times, people speak for us, or they assume what we want.”
- “Something that’s really important is to help people understand the level at which we want to be engaged. We still want to have social activities.”
- “It can really be doing advocacy for yourself – really having to go out and kind of beat the bushes a little bit to find a place where your functioning level and your language fits with needs.”

In terms of accessing support and services to help one cope with the disease, one of the strongest themes was the importance of gaining support by connecting with others, particularly through support groups across a range of delivery modalities.

- “It’s just because of these people who are here, who have inspired me to live and to be positive and to be powerful – anyone who is here who is feeling that they don’t have the power to live their lives fully, know that we are here for each other, and that we can.”

- I cannot tell you how good I feel just to sit around with people that have Alzheimer's and see what they're doing, what struggles they're going through, to hear it all and really do more planning."
- "Support groups are a very important way for us to deal with all of this – managing our lives daily. On the days I'm going to my support group, regardless of how much of a fog or a funk or a physical thud I feel in the morning, not only do the support groups get me going in the morning, I'm usually very charged up after."
- "I don't do very well on the phone, because I can't remember long conversations, so I prefer e-mail. So that got to be my support group. I have early onset people from all around the country and we kind of made our own little support group."

Town hall participants provided a great deal of praise and gratitude for the support programs available through the Alzheimer's Association, and described the benefit not only in their lives, but also in the lives of their care partners. In addition, people highlighted other specific programs or services of interest, many of which are also currently offered by the Association.

- "The first thing I did was pick up the phone and call the Alzheimer's Association and say, 'Okay, I've just been diagnosed and I'm 46 – what are you going to do for me?' And the voice on the other end was very calming and soothing and I knew I had found a second home."
- "I realized that at the time, there weren't a whole lot of early onset folks that were dealing with the Chapter, but they gave me information. They gave me videos. They talked to me. They answered every question that I had, and they started to get me engaged in conversations with other groups."
- "I'm wondering if there could be more opportunity for mental exercises and something that might be provided online that one could access whenever it is convenient, with puzzles or questions or tests or whatever."
- "I know here in Chicago there's something called the Culture Bus that takes people around to museums and things, which is a great activity. I wish there could be a workbook or handbook for chapters across the country to duplicate and replicate that kind of thing."

In addition to community services and resources, a number of individuals have found it helpful to journal, both writing down their experiences, and also connecting with others online to share their stories and perspectives on the disease. Connecting with others online is believed by the participants to not only help provide them with support, as people with Alzheimer's disease, but also is a help to the people around them.

- "When I was diagnosed I felt that I had to write, and I got up out of bed one night and I crept across the hall to the study, and I picked up an envelope and I scratched and scratched and scratched across that envelope, as quickly as I could before what I wanted to write was no longer in my mind and I have a whole notebook like that. And that's how

my journal started, with just creeping out of bed one night and doing that. And I would encourage any of you to journal if you like, write these little things down. If you don't do it, it's gone in a second."

- "I also journal, but I journal on-line. So my family and friends can go to my web site and look and see what's going on with me and through that, anybody in the world can look at that and I get a lot of comments back on that and I get a lot of e-mail from that and those people, again, have become my support group."

## **Advocating and Staying Involved**

A point was made earlier in this report that a diagnosis of dementia often led people to start asking what they really wanted out of life. For many, their new goals included some form of advocacy on behalf of people with dementia. The capacity to tell their stories, raise awareness and serve as advocates is one of the unique benefits of being in the early stage of the disease, rather than the later stages.

In some cases, this advocacy may be individual, private engagements (e.g. telling friends about the disease and helping them understand its impact) or local advocacy (e.g. speaking to community groups about the disease), while in some cases it is advocacy on the state or local level (e.g. testifying in front of state legislators, writing their senator, participating in a rally in Washington DC, or speaking to national media outlets). A common thread in these advocacy and awareness-raising efforts is that they want to help prevent others from going through the same experience they have with Alzheimer's. Their hopes are to improve what they view as ineffective medical treatment and a lack of available drugs or clinical trials, ease concerns among fearful relatives, and reshape inappropriate perceptions by the general public in regard to Alzheimer's disease.

There were also numerous comments about the need for more funding, more research, more assistance, and more understanding of the impact of this disease on people who suffer from it, and on society overall.

It was very important to the participants that they be heard and that they are effective advocates for the needs and issues of people with dementia. This type of activity is described as not only contributing to the larger good, but also as personally therapeutic.

- "I've had opportunities with advocacy work where I talk to certain groups in my community. Even if they don't have the disease, they understand. They're asking for input. They want more information, and they kind of become a support group for me."
- "I had to retire, so I've engaged in focusing all my energy toward helping create advocacy and awareness of the Alzheimer's organization. A lot of times, you must be your own advocate."
- "If we can communicate, we can educate the public, we can educate our friends, we can educate our families. It's really important that we all talk about this so we can educate the public so there isn't this big stigma about Alzheimer's disease."

- “We can do all sort of things until our voices fail us, and then the people who are coming behind us will continue to speak for us”
- “You’ve got to be willing to step forward, let people know you have the disease, and just speak out, because if we don’t speak out now when we can, nobody is going to speak for us later in life.”

Some people also pointed out the absurdity of what they are forced to do because of how government deals with (or does not deal with) the effects of this disease.

- “I am angry. I am beyond angry because those people sitting up on Capitol Hill have the best medical care on the planet, and I have nothing. We’re only allowed three drugs a month. We have to make up our minds which drugs we get. We need help. I had to wait four months to get medication with my Medicaid. That’s way too long. That’s completely uncalled for.”
- “When I applied for aid from the Health Care District for the first time, I was told, ‘That’s no excuse’ when I apologized for being confused due to my Alzheimer’s disease.”
- “I have both Social Security Disability and Medicare. It took approximately two years to get that done and I had to employ an advocate on my behalf, who was very poor. I did all the work.”

There were also many calls for more research, more funding, and more attention. While people with early stage obviously want access to effective healthcare today, they also strive to encourage and accelerate the progress being made toward finding more and more effective treatments, to not only benefit themselves, but also future generations.

- “Now’s the time. Now’s the time to get that breakthrough and get some medications that are going to do more good for more people. All it takes is a phone call or an e-mail to get heard.”
- “We need to educate and we need to let NIH know to keep being funded and we need the money and we need the research and the medications. We need to fight, so please keep your voices going and keep pushing and keep moving.”
- “When people talk about becoming an advocate for this, now I’m starting to learn why. Because I’m wearing the shoes now, where with other people I would just hear about it and I could turn and walk away. So I guess until our government actually hears from the ones who are going through it, or they suffer through it themselves, they’re not going to step up and take the bull by the horns.”
- “The next time you’re in front of your congressman or senator, ask them this question: If you knew without a shadow of a doubt that someone was bringing to our shores a biological weapon of mass destruction that would impact and kill sixteen million Americans in a very cruel and extended long-term manner, what would you as our leader be willing to do to stop them? That’s exactly what’s happening with Alzheimer’s.”

As in other areas, there was also discussion of the unique needs of those with early-onset Alzheimer's, in this case regarding of the age limits on getting assistance. People with early-onset Alzheimer's describe themselves as too young for Medicare, Social Security, or other benefits, and as too young for clinical trials. In their view, they have the same issues as a person who is older with dementia (i.e. the need for expensive medication, inability to work, need for care), but because of their younger age, they are unable to access the same benefits as the older person. They strive to raise awareness of this issue and advocate for change on behalf of the early-onset Alzheimer's community.

- “We can't get into the local transportation system because we're not old enough yet, so I guess I'm asking for any suggestions or help on how we can fit into something – an existing program – or advocate for my assistance on getting people to places where they can be involved and active.”
- “I will probably never live to see any of my pension from eighteen years in the hospital, since the age for Social Security keeps going up and my pension is dependent on my Social Security age.”
- “There is a unique problem for those of us who are working and been informed we are no longer able to perform our duties. We're not financially prepared to retire and there is a significant issue qualifying for various kinds of insurance. I applied for Social Security Disability, only to be told I was ineligible.”

The desire to become involved, stay engaged and remain active in the community extended beyond Alzheimer's-related advocacy. People with early-stage Alzheimer's express the importance of being involved across the board as they felt it was important to be able to reach out and give back in a variety of situations. Civic engagement and social activism are viewed as ways to continue expressing themselves and contributing to society and the greater good.

- “I like to take my experiences and go down to the county where there are disadvantaged kids and work with them down at the county like a second father. It is really rewarding and I think it's really something to give back from a disease you have, and it makes you feel good that you can do something other than have to deal with your Alzheimer's.”
- “I think there's the possibility that we're so concerned with our own things, sometimes we lock ourselves in too much to ourselves, and not enough to the rest of the world. We as a group and as individuals can play a role in trying to change a lot of things and trying to make changes in our society that would be for the good.”
- “I refuse to give up things I've been doing all my life. I work with the Police Department a couple times a week, and I'm very active in my church and in certain other organizations. To the best of my ability, I'm doing exceptionally well in these particular categories.”

# *Summary of Themes*

The intent of this report is to illuminate the experience of being in the early stage of Alzheimer's disease or related dementia and to share the perspectives of those affected on how they wish to be viewed, respected, engaged and treated by the larger field of Alzheimer's professionals and researchers as well as the public at large. Throughout the document, quotes taken directly from people with Alzheimer's disease provide a window into the consciousness of those still capable of offering this level of insight. The themes that emerged from this nationwide discussion outline a roadmap of sorts to offering empowerment and appropriate engagement. This summary of themes is a brief, but telling, review of the perspectives that were shared.

## *The Stigma of Alzheimer's and its Impact on Relationships*

The overriding theme influencing much of the discussion is that people in the early stage of Alzheimer's are misunderstood because of myths and misconceptions about the disease and that this misunderstanding leads to a dominant negative stigma associated with having the condition. People with early-stage Alzheimer's repeatedly point out that they are living with Alzheimer's, not dying from it. They acknowledge the fears and uncertainties that accompany a diagnosis but seek support in remaining viable and respected members of society, retaining their personhood and ability to contribute.

Negative associations with Alzheimer's disease are shown to have a direct impact on the relationships between people with the disease and most everyone with whom they come into contact. People described the change in interactions that occur with their family and friends, colleagues and co-workers, as well as with the medical community. People with early-stage Alzheimer's seek to work together with all those in their life to improve their interactions in a way that will result in their continued positive involvement and acknowledgment of their ideas and contributions as valid. Demonstrating a strong desire to be active in advocacy and awareness-raising, the challenge is set to diminish the existing stigma and enable the continuation of their personhood.

## *Dissatisfying Interactions with the Medical Community*

People with early-stage Alzheimer's report significant challenges in effectively navigating both the diagnostic process and the follow-up treatment and care they receive. They express difficulty securing a valid and timely diagnosis, particularly those with early-onset Alzheimer's, and describe a severe burden associated with the current diagnostic testing procedures. Once Alzheimer's is identified, they seek more complete information about what to expect and the steps that can be taken to enhance their quality of life, both in terms of available medications and community resources.

There is a strong desire to participate in research and make contributions to the larger field of scientific inquiry to gain both potential benefits for themselves as well as to aid future generations of those affected by this disease. They outline potential barriers to this contribution, specifically critiquing the present eligibility criteria for inclusion in research.

### *Uncertainty about Availability of Support Services*

A lack of knowledge about accessible and appropriate support services available in communities was repeatedly expressed. Still, they acknowledge the benefit of the services that are available, and in which they have participated. Specifically, they highlight the importance of securing appropriate support, and seek support groups that are offered in various modalities to connect with others that have a shared understanding of their experience.

Further, they describe the need for expanded and enhanced support services to educate them about the disease and what to expect, while keeping them apprised of new developments in available research and emerging treatments to fight their decline. There is a pronounced need for improving existing support services and increasing accessibility of these services.

### *Sources of Major Concern in Daily Life*

People with early-stage Alzheimer's recognize the changes that are taking place in their own independence and functional ability. A major fear expressed in this discussion is the continued decline in independence and the prospect of becoming increasingly reliant on loved ones and other care providers. There is a hope that recognition of these fears will lead to their own personal inclusion in the decision-making process and that their involvement will lay appropriate plans across a range of areas to help minimize the negative consequences of disease progression.

In particular, a major fear was expressed about the impact on their ability to continue driving. Viewed as a proxy for overall independence, there is a hope to remain as independent as possible, for as long as possible. They propose and seek solutions that will enable them to meet this need over time, and in a manner that preserves their safety.

### *Desire to Stay Involved and Make a Difference*

Perhaps above all else, people in the early stage of Alzheimer's demand to be heard and fight to remain engaged as contributing members of their community. They wish to be included in everyday activities and remain social. They hope to have the opportunity to take advantage of the abilities they retain to make a difference by raising awareness among the public and advocating for change. Whether in their local community or with federal policy makers, they hope to tell their story and in doing so, put a "real face" on this disease.

If they are enabled to continue participating in the activities they have always enjoyed then the current practice of dwelling on their condition and treating them as a disease will be assuaged. In their hearts, people with early-stage Alzheimer's want to enjoy life and they demand that those without the disease assist them in achieving their pursuit of happiness to the extent possible.



## **Conclusion**

It is well known that Alzheimer's disease is complicated and ultimately devastating to those who live with the disease. As it gradually progresses, it impacts not just the individuals affected, but also their families and friends. Further, today Alzheimer's disease remains fatal. But, the late manifestation of the disease no longer represents the whole picture of how people with Alzheimer's are affected. This report brings a much needed perspective that highlights the experience of those that have not yet progressed to the point of requiring comprehensive care services. Rather, they retain many of their capabilities, seek to remain as independent as possible and contribute to the world around them. People in the early stage of dementia seek to partner with others to express themselves and to remain the people they have always been, despite their condition.

A first step to better understand the unique needs of people with early-stage dementia has been taken through this nationwide discussion of Alzheimer's by people with Alzheimer's. Going forward, there is a shared responsibility -- for people with or without the disease -- to preserve humanity and work toward a world that welcomes the contributions of people living with Alzheimer's disease.

# *Appendix: Sample Meeting Agenda*

**Alzheimer's Association  
Early Stage Town Hall Meeting  
Oakland, California  
July 28<sup>th</sup>, 2007**

## **Agenda**

***“The Experience of Early Stage Alzheimer's Disease –  
How are you affected, How can we Help?”***

- Registration & Continental Breakfast 8:00
- Opening and Welcome 9:00
  - *William Fisher, CEO, Northern California and Northern Nevada Alzheimer's Association*
- Welcome and Introduction of Co-Hosts
  - *Angela Geiger, National Vice President, Alzheimer's Association*
- Introduction of Meeting by Co-Hosts 9:05
  - *Professor Hank Greely, Stanford Law Professor – Co-Host and Moderator*
  - *Chuck Jackson, Early Stage Advisor – Co-Host*
- Panel Discussion 9:15
  - *Carol Kirsch, a person with early stage Alzheimer's disease sharing her perspective.*
  - *Judy Filipoff, a member of the Association chapter staff to offer perspective on current care and support services available for early stage.*
  - *Dr. Adam Boxer, UCSF Memory and Aging Center, a clinician/researcher to describe available and emerging treatments.*
- Structured Discussion 9:30

*The moderator opens the floor up for comments, questions, concerns and discussion from the early stage participants. Each participant is given 3-5 minutes to ask questions or to discuss their perspective on the given topic.*

**1 - Interactions with Medical Community**

- Diagnosis
- Available Treatments/Medicines
- Participation in Research

**2- Changes in Daily Life**

- Loss of independence / Coping with changes in function
- Changes in roles and relationships (personal or professional)
- Safety Issues (driving, wandering, home safety)

**3- Engaging Community Resources (Availability and Access)**

- Care and support services
- Meaningful activities and social opportunities

- Break 11:00
- Open Discussion 11:10

*Participants may comment or discuss any topic of interest (with an overarching theme of how the Association may assist).*

- Closing Remarks 12:00

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