

# National Alzheimer's Project Act (NAPA)

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The information that follows was included as an attachment to an email submitted by the public.

For more information about NAPA, visit the NAPA website at:

<http://aspe.hhs.gov/national-alzheimers-project-act>



## ABOUT THIS REPORT

*Alzheimer's from the Frontlines: Challenges a National Alzheimer's Plan Must Address* summarizes the major challenges Americans report they face from Alzheimer's disease and related dementias. Over 43,000 people across the country participated in the Alzheimer's Association's public input process to share their insights, concerns and hardships. Ten key issues emerged that they believe the U.S. Secretary of Health and Human Services must address in the National Alzheimer's Plan now being created through the implementation of the National Alzheimer's Project Act (NAPA):

- A lack of public awareness
- Insufficient research funding
- Difficulties with diagnosis
- Poor dementia care
- Inadequate treatments
- Specific challenges facing diverse communities
- Specific challenges facing those with younger-onset Alzheimer's
- Unprepared caregivers
- Ill-equipped communities
- Mounting costs

For current information on this campaign, and the creation and implementation of the National Alzheimer's Plan, please visit [www.alz.org/napa](http://www.alz.org/napa).



Now is the time for Alzheimer's disease to be a national priority.

We know this from the numbers. As many as 5.4 million Americans are living with Alzheimer's today supported by nearly 15 million unpaid caregivers. By mid-century, as many as 16 million Americans could have the disease.

We know this from the impact. The annual cost of Alzheimer's today is \$183 billion, up \$11 billion over the prior year. By mid-century, Alzheimer's could cost this country over a trillion dollars per year — in today's dollars.

We know this from the devastating nature of this disease. Alzheimer's irreversibly robs people of their very selves. It also exacts a significant toll on the millions of family members and friends who must both witness and often provide exhaustive, round-the-clock care as their loved ones succumb to the disease.

Yet Alzheimer's disease now stands as the only cause of death among the top 10 in the United States without a means to prevent, cure or even slow its progression.

We've heard it before, but never as loudly expressed as during the Alzheimer's Association's public input process. The Association hosted 132 public input sessions nationwide this summer to inform the implementation of the National Alzheimer's Project Act. More than 43,000 individuals — those with Alzheimer's, caregivers, providers, researchers, health care professionals, community leaders and many other stakeholders — participated, offering views and perspectives on the challenges that must be addressed in the National Alzheimer's Plan. Thousands of individuals spoke up — honestly, passionately and courageously — to tell the nation's leaders how Alzheimer's affects and forever changes lives.

Now we have a new and important opportunity to change the course of Alzheimer's disease through the creation of the National Alzheimer's Plan.

To fulfill this opportunity, the National Alzheimer's Plan must be urgent and transformational, achievable and accountable. In the following pages you'll read — in participants' own words — about the challenges millions of American families face each and every day as they live with the painful realities of Alzheimer's. And from these challenges, we can see the outline of the National Alzheimer's Plan.

Based on all of their input and all of their experiences, here is what the National Alzheimer's Plan must do.

**Increase awareness of the impact of Alzheimer's disease.** Despite the number of people affected, many Americans still know very little about this disease. It still too often remains in the shadows, discussed in whispers if at all. We must bring Alzheimer's fully into the open, explain the warning signs, address misplaced anxieties, correct misconceptions and overcome the stigma that too often makes a terrible disease even more of a hardship.

**Real treatments faster.** The ultimate goal is a treatment that can completely prevent or cure Alzheimer's, but we know that even treatments that simply delay onset of the disease or slow its progression could have a dramatic impact on the quality of people's lives, federal spending and our nation's economy. With appropriate levels of research funding — levels we are far below today — and an enhanced review process, we can accelerate the discovery and delivery of these desperately needed treatments.

**Better care now.** We must change the quality of care provided to those with Alzheimer's. Care today is often fractured and ineffective, falling far short of what is needed. Detection and diagnosis, the foundation of good care, often happens far too late, if at all. As a result, many facing the disease today experience poor care coordination and further complications from coexisting conditions.

**Better support today.** We must change the fact that we are very poorly equipped to support those with Alzheimer's and their caregivers in our homes, communities and long-term care facilities. Caregivers are too often isolated and uninformed about effective support strategies. Little government support is provided to help those who want to keep their loved ones at home longer, even if this option is less expensive to our country overall. The present reality is that even long-term care facilities are often ill-equipped to meet the intense demands of caring for those in the middle and later stages of the disease.

**Change for all.** African-Americans and Hispanics are more likely to develop Alzheimer's and less likely to have a diagnosis. Rural populations have limited access to support services, and immigrant communities face cultural and language barriers. This plan must address disparities in diverse and underserved communities.

This is an achievable agenda, and it is the right agenda. We've learned many things from the Alzheimer's Association's public input process, but the most important is this: Americans living with and affected by Alzheimer's disease are desperate for decisive and meaningful action by the federal government.

We need a transformational plan. We need it urgently. It's time to roll up our sleeves and get it done.

A handwritten signature in black ink, appearing to read 'Harry Johns', written in a cursive style.

Harry Johns  
Alzheimer's Association  
President and CEO

# acknowledgements

The Alzheimer's Association would like to especially thank each of the over 43,000 people nationwide who participated in this groundbreaking Alzheimer's public input campaign. Without their participation in these events to share their experiences and offer their insights regarding the challenges that must be addressed through a transformational and achievable National Alzheimer's Plan, this report would not be possible.

The Alzheimer's Association is deeply grateful to the White House and the U.S. Department of Health and Human Services for their support of the National Alzheimer's Project Act and participation in this public input process.

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Alzheimer's Association - Central and Western Virginia Chapter

Alzheimer's Association - Central Illinois Chapter

Alzheimer's Association - Cleveland Area Chapter

Alzheimer's Association - Colorado Chapter

Alzheimer's Association - Delaware Valley Chapter

Alzheimer's Association - Desert Southwest Chapter

Alzheimer's Association - East Central Iowa Chapter

Alzheimer's Association - Eastern North Carolina Service Area

Alzheimer's Association - Eastern Tennessee

Alzheimer's Association - Georgia Chapter

Alzheimer's Association - Great Plains Chapter

Alzheimer's Association - Greater Cincinnati Chapter

Alzheimer's Association - Greater East Ohio Area Chapter

Alzheimer's Association - Greater Idaho Service Area

Alzheimer's Association - Greater Illinois Chapter

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Alzheimer's Association - New Mexico Chapter

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# understanding and addressing the alzheimer's disease crisis

Alzheimer's disease is an escalating national epidemic. As many as 5.4 million Americans have Alzheimer's today, and more than half of Americans know someone with the disease. One in eight people aged 65 and older have Alzheimer's disease, and nearly half of people aged 85 and older have the disease. Someone new develops Alzheimer's every 69 seconds. Almost 15 million unpaid caregivers care for these individuals and those with other dementias.

As baby boomers age, one in eight will develop Alzheimer's. By mid-century, as many as 16 million Americans will have Alzheimer's. It is the sixth-leading cause of death in the United States, and yet it is the only cause among the top 10 without a way to prevent, cure or slow its progression.<sup>1</sup> Already, Alzheimer's kills more people than diabetes and more people than breast cancer and prostate cancer combined.

Alzheimer's is also a heartbreaking disease. Symptoms gradually worsen over time, changing from limited memory loss, to greater confusion, to loss of personality, to the inability to carry on a conversation, to complete loss of independence. It slowly robs individuals of their memories, autonomy and, ultimately, life. Caregivers of people living with the disease are burdened emotionally and physically. They stretch themselves to their limits to provide appropriate care while simultaneously trying to manage their own livelihoods and health.

If the human toll were not enough, consider the economic costs. In 2011, caring for those with Alzheimer's will cost American society an estimated \$183 billion — \$11 billion more than last year. Most of this cost is covered by Medicare and Medicaid. Medicare payments for beneficiaries with Alzheimer's and other dementias are three times greater than for comparable beneficiaries without these conditions. Medicaid payments are nine times greater. Between now and 2050, Medicare spending on those with Alzheimer's and other dementias will increase nearly 600 percent, and Medicaid spending will increase nearly 400 percent.<sup>2</sup>



## The National Alzheimer's Project Act (NAPA)

The National Alzheimer's Project Act (Public Law 111-375) requires creation of a national strategic plan to address the rapidly mounting Alzheimer's crisis and will coordinate Alzheimer's disease efforts across the federal government. More specifically, the law requires:

- An annually updated national plan submitted to Congress on how to overcome Alzheimer's
- Annual recommendations for priority actions to both improve health outcomes for individuals with Alzheimer's and lower costs to families and government programs
- The annual evaluation of all federally funded efforts in Alzheimer's research, care and services, as well as their outcomes
- The creation of an Advisory Council on Alzheimer's Research, Care and Services

By making Alzheimer's a national priority, the United States has the potential to create the same success that has been demonstrated in the fights against other major diseases. Federal leadership has helped lower the number of deaths from conditions such as HIV/AIDS, cancer and heart disease. NAPA will allow Congress to assess whether the nation is meeting the challenges of this disease for families, communities and the economy. Through its annual review process, NAPA will, for the first time, enable Americans to answer the simple question, "Did we make satisfactory progress this past year in the fight against Alzheimer's?"

<sup>1</sup> Alzheimer's Association, *2011 Alzheimer's Disease Facts and Figures* (2011).

<sup>2</sup> Alzheimer's Association, *2011 Alzheimer's Disease Facts and Figures* (2011).

# understanding and addressing the alzheimer's disease crisis

## Public input for a National Alzheimer's Plan

As one of the top priorities for the Alzheimer's Association, and the focus of thousands upon thousands of Alzheimer's advocates from across the country, NAPA provides the essential framework needed for overcoming Alzheimer's disease. With this in sight, the Association urged this same grassroots network to eagerly participate in its implementation. To support a National Alzheimer's Plan and ensure public participation in the planning process, the Alzheimer's Association gathered input from Americans across the country on the leading issues that a National Alzheimer's Plan must address.

From the public input, ten major challenges emerged:

1. **A lack of public awareness.** This includes a lack of knowledge and widespread misunderstanding about Alzheimer's; significant stigma and negative experiences that affect personal and professional relationships; and a poor understanding of the scope of the disease.
2. **Insufficient research funding.** Because there's no way to prevent, stop or slow the progression of Alzheimer's, many expressed feelings of powerlessness to help themselves or future generations and called for bold action to secure a brighter future.
3. **Difficulties with diagnosis.** Challenges lead to delayed diagnosis, poor experiences in the diagnostic process, missed opportunities to immediately connect families with available support and a lack of documentation in a patient's primary medical record.
4. **Poor dementia care.** Communication barriers with health care providers and allied health professionals, care coordination issues with providers, and a lack of knowledgeable personnel equipped to meet the unique needs posed by Alzheimer's and other dementias results in poor quality of care.
5. **Inadequate treatments.** Effectiveness of available drugs varies across the population, but none of the treatments available today alter the underlying course of this terminal disease.
6. **Specific challenges facing diverse communities.** Given the disproportionate impact of Alzheimer's on ethnic and minority populations, efforts must be implemented to eliminate disparities in these communities.
7. **Specific challenges facing those with younger-onset Alzheimer's.** Preconceived notions of Alzheimer's and age can delay diagnosis, act as a barrier to participation in research or government programs and make it difficult to find long-term care appropriate for younger populations.
8. **Unprepared caregivers.** Caregivers need critical support to provide in-home care but have trouble finding affordable services and education to care for a loved one, and to alleviate the emotional and physical burden of caregiving.
9. **Ill-equipped communities.** Many places are unprepared to address the individualized needs of people living with Alzheimer's, especially those in rural areas.
10. **Mounting costs.** The costs to treat and care for Alzheimer's can be tremendously high and unaffordable over time and even more difficult to bear when encountering barriers to qualifying for insurance or government support.

It is the Alzheimer's Association's expectation that the challenges captured in these broad themes, as well as the views, comments, insights and perspectives from members of the Alzheimer's community contained in this report, will help to inform and educate the nation's leaders as they embark on the development of the National Alzheimer's Plan. These thousands of participants spoke on behalf of all Americans counting on this effort to change the trajectory of this devastating disease for the millions affected today and the millions more at risk tomorrow.



# methodology



Public input sessions were typically one hour in length, and participants were asked to limit comments to ensure maximum participation. At many sessions, a panel comprising government officials, community leaders and Alzheimer's Association staff received the input. Each session was hosted by a facilitator who explained the format guidelines and managed the input process. While participants were invited to share their thoughts on any subject related to Alzheimer's disease and other dementias, the facilitator occasionally provided common topics heard within the Alzheimer's community to solicit views on a range of issues, including the health care system, research and treatments, and long-term care and support services.

Public input sessions varied in the number of participants and listening panelists. National input sessions attracted larger crowds, from 175 to over 600 participants.<sup>3</sup> Local input sessions ranged from 4 to 500 participants. All sessions were held in handicap-accessible locations that could accommodate the number of participants. Types of locations varied depending on size and availability and included hotel ballrooms, community centers and local churches. When appropriate and available, Association staff used microphones, speakers and audio or video recorders to make inputs easier to hear and to document feedback.

For those unable to share their thoughts in person, the Alzheimer's Association encouraged the public to submit input online at its National Alzheimer's Project website, [www.alz.org/napa](http://www.alz.org/napa). In addition to submitting input online, visitors to the website could also learn more about the National Alzheimer's Project Act and how to get involved in the fight against Alzheimer's disease. From May through October, the Association collected over 4,000 submissions online from all 50 states, the District of Columbia and Puerto Rico.

The Alzheimer's Association also hosted a Telephone Town Hall input session on August 4 to accommodate those who could not attend an input session in person and had limited or no access to the internet. Over 32,000 people participated in this telephone session from 49 states, the District of Columbia and Puerto Rico.

This report and data analysis are not based on scientific study or rigorous quantitative analysis. Chapters submitted reports summarizing comments at public input sessions, recorded comments by video and/or audio when available and a few collected handwritten comments from participants. All comments received online, in person and by phone were reviewed by the Association and sorted into broad categories based on challenges described in the public input. Comments were then analyzed for key themes within each category and summarized into this report of major issues identified by public respondents regarding the challenges they wanted to be addressed in a National Alzheimer's Plan. Similarly, conclusions contained in this report are qualitatively derived from the feedback received from respondents nationwide.

<sup>3</sup> The first national public input session was held during the Alzheimer's Association Advocacy Forum, which drew approximately 620 participants.

## a lack of public awareness of alzheimer's disease



Despite the growing number of Americans directly affected by Alzheimer's disease, there are still widespread misconceptions of the disease. Those that participated in the Association's public input process cited an extensive lack of public awareness of Alzheimer's. Compared with other major diseases, Alzheimer's appeared to be less known and more likely misperceived as a "normal part of aging." Even lesser known is younger-onset Alzheimer's, which strikes individuals under the age of 65. Many people said the lack of public awareness is a primary reason for reduced public sympathy, insufficient resources dedicated to addressing Alzheimer's and under diagnosis.

*"Nearly everyone that I come in contact with has no understanding of what it is like to have Alzheimer's. When I describe anything that goes on with my mother, they are always surprised." – Lake Isabella, MI*

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*"I am in my mid 40s and am having some of the same symptoms my father had. I am at high risk for this disease. And that is scary enough. I want to see commercials to show the early onset. **I am so tired of not being heard.**" – Lancaster, OH*

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*"Everywhere I turn, I see awareness and education for breast cancer. Don't get me wrong. I completely understand the importance of that and fully support the cause. But I cannot wait for the day when just as many folks are educated and have the compassion for individuals and families impacted by Alzheimer's." – Seville, OH*

*"More information about the disease and how to get help needs to be publicized in media, especially television. Increased awareness of the disease and proper diagnosis will help the diagnosed person and their family seek help earlier in the disease process. This will enable them to prepare financially, seek necessary medical care and participate in clinical trials that one day may bring about a cure." – Newport News, VA*

*"...Let the public be more aware of what has been discovered about this disease through television, websites and newspapers. Hopefully, the more people that are aware of what is going on, the more people we will have to help us." – Sugar Land, TX*



## a lack of public awareness of alzheimer's disease

Misperceptions of Alzheimer's can also lead to painful experiences and stigma. Many people said stigma stemmed from the public's lack of understanding of the disease or its symptoms, often inappropriately referring to it, for instance, as just a part of aging. Sources of stigma range from fear of the disease to shame for having it. Unfortunately, these biases surrounding Alzheimer's can keep many from seeking or sharing a diagnosis and compound the isolation and depression that often accompanies the disease.

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*"At times, some doctors implied that we should not talk with others about my husband's condition, **as though it was something to be ashamed of.**"*

*– Tulsa, OK*

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*"Family members, friends and strangers all treat these people as if they chose this lifestyle, or as if they are crazy when in fact that is not the situation at all." – Lockport, NY*

*"Just as cancer was the big C word no one wanted to say, Alzheimer's disease must be talked about more to help us support each other better for a longer quality of life."*

*– Clinton, IA*

*"When you talk about Alzheimer's, the reaction you receive both at work and in public is one of it's a disease for 'old people.'" – Kissimmee, FL*

*"...His friends say to me 'How do you communicate with him?' People just do not know how or what to do or say if they were to see him." – Bartlett, TN*



## insufficient research funding



Alzheimer's is a fatal condition with no known means to alter the underlying course of the disease. Many describe receiving an Alzheimer's diagnosis as a devastating experience that upends relationships, careers, finances and future plans. Because of this, many who participated in the public input process stated that coping with the current realities of Alzheimer's and sustaining hope and optimism in the midst of this disease is a huge challenge. People want more. They want a public commitment to overcome Alzheimer's.

Participants repeatedly linked hope with research, signifying that no single development would have a more sweeping impact and offer more hope than the advent of an Alzheimer's therapy breakthrough — a treatment that prevents, stops or slows the progression of the disease. In recent years, many Alzheimer's drug candidates that were thought to be promising failed during clinical trials, indicating to numerous public input participants that there is a need for more federal dollars for research to prevent or cure Alzheimer's. This also appears to match general public opinion. In a recent survey conducted by the Harvard School of Public Health, almost 67 percent of U.S. respondents said the government should increase spending for Alzheimer's research.<sup>4</sup>

*“Nationally, the cost of Alzheimer's care is many times the amount of funding being committed to Alzheimer's research. This is NOT a recipe for success. Reductions in heart disease, cancer and AIDS are examples of progress in disease reduction when sufficient funds are appropriated for research.”*  
— Port Hueneme, CA

*“This is what frustrates me the most. We live in a country where we spend millions of dollars for our favorite sports teams but can't spend the same money to find a cure for this disease.”*  
— Dallas, TX

*“More aggressive research is needed in order to understand the disease and how to PREVENT it in the first place. Prevention is always better than treatment.”* — Georgetown, TX

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*“If we are going to get through the next 20 or 30 years — watching baby boomers with Alzheimer's increasingly burden their children with a disease they cannot control — **we absolutely have to invest in the research to find good treatment options.**”*  
— Roseville, CA

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*“An Alzheimer's disease diagnosis is worse than a stage 4 malignant cancer diagnosis — with Alzheimer's there is NO hope of beating the odds. As a member of a family that has genetic younger-onset Alzheimer's disease (we get it in our 40s), I am increasingly concerned about the lack of research funding. Our family participates in research to help all Alzheimer's patients, but we need more federal funding to make the needed impact.”* — Mechanicsburg, PA

*“They need to change the mix at NIH. Going from \$500 million to \$2 billion — they need to change the mix. It's not politically correct to say take it away from some other disease, but a real assessment of what needs to be done is what is necessary.”* — Santa Barbara, CA

<sup>4</sup> Blendon RJ., Georges J., et al. Key Findings from a Five-Country Survey of Public Attitudes about Alzheimer's Disease. Poster presented at Alzheimer's Association International Conference, July 2011.



## insufficient research funding

Public input participants also recognize the limits of today's research for novel ideas. New scientists enter the field every year with fresh proposals, but fewer and fewer of them receive the necessary grants to begin their own new basic research. The result is a stagnant pipeline of testable theories and risk-averse concepts that lack the innovation necessary to address major diseases. Translational research is even more competitive and has even less funding available to assist researchers in demonstrating the potential for successful application of their ideas. Rather than being a critical step in the process toward clinical research and potential new therapies, translational research is described as the “valley of death,” or bottleneck in today's research opportunities.<sup>5</sup>

*“In spite of the tremendous resources and activity of biotech companies, major pharma companies with R&D and university-based research, in addition to government-funded research programs, many initially promising therapies have failed during their course of development. Clearly, more innovative thinking needs to be brought to the table, in terms of preclinical and clinical research, to develop effective treatments for this awful disease.” – New York, NY*

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*“Most people affected by the disease find a way to meet the challenges, with or without public support. But they can't find the cure. That takes qualified researchers. **Public investment in research should be job one.**”*

*– Moline, IL*

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*“The best hope we have of stemming this epidemic is through investments in research now. Right now, federal funding for Alzheimer's research is at a historic low, with less than one in 10 grants submitted actually funded. The total amount on investments into Alzheimer's research needs to increase substantially from the \$450 million today to \$1 to \$2 billion in order to translate today's basic research findings into tomorrow's treatments.” – Cleveland, OH*

*“My other big concern is there is a — maybe ‘army’ is a good word — of passionate, excited young people who want to devote their careers to the study of Alzheimer's disease. And these are people from whom the cures are going to come. These are people who have the new ideas, who are willing to work 80 hours a week in the lab. And if they don't get the support and the resources that they need to study Alzheimer's and to understand it, we're going to lose a lot of time and a lot of young scientists.” – San Francisco, CA*

<sup>5</sup> FasterCures, *Translational Research: Crossing over the Valley of Death*, January 2011.

## insufficient research funding



Developing new treatments is a lengthy, expensive and uncertain process. Therapies to treat the central nervous system can take 15 to 20 years to develop, longer than any other class of drugs. The length of time is discouraging for many individuals affected by the disease, particularly those with multiple family members affected. Drug companies are also discouraged, and the high risk associated with neurological research and development is leading to a decline in private sector investment.<sup>6</sup> Many comments from across the country described the need for more research, particularly to answer how Alzheimer's disease passes through generations and what can be done to stop it.

*"My mother had early-onset Alzheimer's. She passed away at the age of 62 after having the disease for over 12 years. I also have a sister who has early-onset. I have 13 siblings. What are the odds that more of us will get Alzheimer's?" – Lorain, OH*

*"There is an extended genetic bloodline of the disease on my deceased (age 53 in 2008) wife's side of the family, with four members over the last two generations that have passed, and one that is still alive at age 52. I am also concerned about my twin sons, age 17, and their possible genetic predisposition to the disease in the future." – Hamden, CT*

*"In the 21 years since an autopsy specified my mother's Alzheimer's, dementia research has mostly consisted of the very limited success of pharmaceutical trials and more recent genetic testing. This tunnel vision has resulted in my family's continuing tragedies." – Berkeley, CA*

*"There seem to be no consistent medical protocols for dealing with genetic questions and concerns from family members, and it is difficult to get direction as to how to proceed concerning possible genetic testing." – Tulsa, OK*

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*"I'd like to see more trials for those with early-onset. Let those with a genetic history join a study or trial long before the signs are there. For example, I'm 38; **I'd like to know my options now before the disease starts to show itself.**" – Virginia Beach, VA*

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<sup>6</sup> Stovall, Sten. (2011, March 27). R&D Cuts Curb Brain-Drug Pipeline. *Wall Street Journal*. Retrieved September 27, 2011, from <http://online.wsj.com/article/SB10001424052748704474804576222463927753954.html>.

## difficulties with detection and diagnosis

According to participants, detecting and diagnosing Alzheimer's disease is frequently a very difficult and challenging experience. Diagnosing Alzheimer's takes more time than physician visits generally allot for an appointment, and system issues such as provider time, costs and reimbursements can contribute to poor experiences. Families feel rushed out the door because doctors have to move on to their next appointment. The lack of meaningful dialogue between physicians and those seeking assistance raises serious communication concerns about the ability to obtain a diagnosis, especially by those who face language barriers. It also raises questions about physicians' ability or desire to diagnosis Alzheimer's. They may not be trained in detection of the disease, or they may feel a diagnosis is of no value because no disease-modifying treatments exist. Some mistakenly presume Alzheimer's or other dementias are a normal part of aging. Health care providers who are properly trained in assessing dementia may also be reluctant to give a formal diagnosis because of implications attributed to a diagnosis, or before fully exhausting other possible causes.<sup>7</sup>

Many participants described delays in diagnosis due to the amount of time it would take doctors to "rule out" other conditions and the challenge of finding a trained physician to perform appropriate evaluations. Others told of having to visit doctor after doctor before finding one willing to make a diagnosis.

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*"It took about **eight years of chasing symptoms** before we were given a diagnosis." – Tampa, FL*

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*"My husband was diagnosed at the age of 55 but not before we had gone through doctor after doctor getting a proper diagnosis. Too many of the doctors brushed his symptoms off as depression or a mid-life crisis. One even had the nerve to say it was my fault he was having difficulties!" – Kewanee, IL*

*"The clinical criteria for Alzheimer's and other dementias are much too restrictive, especially when it comes to age. They require many expensive tests to rule out every other possibility. From my experience, Barb's first MMSE test was proof that something was wrong. A teacher who taught second-graders about telling time suddenly couldn't draw a clock face and put the numbers in the right place, yet she 'passed' the overall test! Give me a break!" – Dixon, CA*

*"Diagnosis took a long time (five-plus years) and many tests later, ruling out every other possible option."  
– Virginia Beach, VA*

<sup>7</sup> Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures (2011).

## difficulties with detection and diagnosis

An Alzheimer's diagnosis is just part of the challenge. Those who receive a diagnosis often find themselves left with questions on what to expect and where to get help. This information is a fundamental, but often missed, step in the diagnostic process and can deprive people of the potential benefits of appropriate care planning while imposing unnecessary emotional burdens on families. Many commented on wanting more information in their doctors' office following an Alzheimer's diagnosis, but being left to figure it out on their own.

*"He was diagnosed at 53 and had a job where he traveled around the world and did a lot of very active things. He was suddenly diagnosed. His doctor told him, 'Do not ever get [on] a plane by yourself' and he said, 'I need help transitioning' to being an active man in the community to a man sitting here not being able to talk." – Chicago, IL*

*"This doctor did nothing to provide information, resources or help for my mother in the caregiving role. He gave her meds and said that was all they could do!" – Dover, FL*

*"Doctors are neglecting their patients when they 'prescribe' treatment and then show the patient to the door." – Aurora, IL*

Identifying Alzheimer's in its early stages allows affected individuals to participate in their own care process, including treatment options, clinical trials, long-term needs and financial and legal issues. There is evidence that supports significant public interest in early testing for Alzheimer's disease. In a survey of five countries by the Harvard School of Public Health and Alzheimer Europe, 89 percent of respondents in the United States — and 95 percent of respondents aged 60 and over — said that if they were exhibiting signs of confusion and memory loss, they would see a doctor to determine if the cause was Alzheimer's. Sixty-five percent of American respondents also said they would be likely or very likely to get a test for early diagnosis of Alzheimer's if one were available before they exhibited signs of the disease.<sup>8</sup>

Of the public input received, many people believe that early detection is vital in preparing for a life of living with Alzheimer's disease. This was especially evident among those with familial history of Alzheimer's who have already experienced the physical, emotional and financial effects of this disease. Many conveyed their concerns of imposing a significant burden on their loved ones and urgently expressed their desire for early detection to become a routine regular practice during all doctor visits.

*"My biggest concern today is how to encourage/educate the public, the clinician and the payers on the importance of early detection of the disease while it is still possible for doctors, patients and family to make the best decisions on lifestyle changes and life planning." – Carlisle, MA*

*"Earlier diagnosis could keep more people in their homes longer and thus reduce the overall cost of health care dollars for this devastating disease." – Columbus, OH*

*"I would like to see that people can get tested for Alzheimer's easily and early with very little out-of-pocket expense on the patients' part. Doctors should recommend a test be done if there is a history of it in your family and that test be done at as early of an age as is possible." – Kent, WA*

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***"Earlier diagnosis would have given her many more years of a comfortable life at home with her family. Instead, we had to make the tough decision to place her in a nursing home, which only increased her confusion and paranoia." – Dupont, WA***

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<sup>8</sup> Blendon RJ., Georges J., et al. *Key Findings from a Five-Country Survey of Public Attitudes about Alzheimer's Disease*. Poster presented at Alzheimer's Association International Conference, July 2011.



## difficulties with detection and diagnosis

The last step in the diagnostic process is documentation of the diagnosis. An individual's medical record is the primary documentation for all medical history, co-morbidities, therapies and their outcomes. Health care providers look to it to inform care recommendations and next steps. Thus, documenting a diagnosis of Alzheimer's disease in an individual's medical record is a crucial step toward comprehensive care. Unfortunately, it is not always done and can contribute to problems in managing other chronic conditions and to delays in health care providers' understanding of what should be detected, diagnosed, treated and managed for the overall health of the patient and caregiver.

*“Having been the primary caregiver for my father for over 10 years, we found it very difficult to find the right resources and programs that fit his needs. He had several other health issues; managing and updating the information between the doctors was a constant battle. The plan needs to include a system that streamlines the flow of information throughout the medical community, i.e., electronic health records.” – Ashburn, VA*

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*“I have early-onset Alzheimer's, and it was a frustrating two years to get a diagnosis. **The diagnosis still remains unnamed in my medical records.**” – Nashville, TN*

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*“There is tremendous confusion when people go out to the hospital. Hospitals seem to want to re-diagnose what has already been established. This can be helpful, but sometimes it just gets out of control. I had to repeat, repeat, repeat medical histories over and over and over, and it just gets exhausting.” – New York, NY*

*“What I would like to see in legislation is comprehensive and accessible electronic medical records for the professionals to be able to work with dementia patients and for the families to be able to understand what is happening for their loved one medically speaking.” – Frederick, MD*

## poor dementia care

Participants stressed the critical importance of effectively connecting with health care providers and allied health professionals in the Alzheimer's journey. These medical professionals are the gatekeepers to diagnoses, treatment options and information on what to expect on the long road ahead. They are often the primary source for medical record history, specialist referrals, and information on clinical trials and other research opportunities. They are also the frontline work force meeting day-to-day needs of people living with Alzheimer's, providing essential support services as the disease progresses over the long term.

But they also made clear that making these effective connections can be a tremendous challenge. People who do not get information following an Alzheimer's diagnosis are left to piece together appropriate next steps, coordinate care among multiple providers and identify appropriate long-term support in a complicated health care system. For many who participated in the public input, this aspect of finding, organizing and managing care is just too much.

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***“What’s out there now is a patchwork of people and agencies who don’t know who else is out there or what services they provide.***

*It’s a nightmare, and it is no better now, when I am trying to take care of my mother, than it was 15 years ago when I was my grandfather’s caregiver.”*

*– Hebron, IN*

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*“Usually, families are on their own in finding each of these health care professionals, and then one doesn’t know what the other is doing.” – Danville, IL*

*“My greatest frustration, with a wife who was diagnosed with Alzheimer’s in 2007, was to obtain information and support from one central organization, office or location regarding all aspects of this disease to include diagnosis, follow up, applicable medication, caregiving, financial aid, alternatives and basic chronological responsibilities regarding these issues. This process is currently so fragmented, different and confusing within the medical community, local, state and the national government that it causes major problems for both the patient and the caregivers involved.” – Grovetown, GA*

*“Physicians, especially neurologists, should have packets of resource information available for any family that is given a memory illness diagnosis.” – Saline, MI*

Many people pointed to the need for a care coordinator who could counsel a newly affected family through the care process and could also describe potential challenges ahead. Such a person would have been helpful, they suggested, in addressing the many questions and relatively few answers that often accompany a new diagnosis.

*“Having a care manager available to assist in accessing services would be very helpful, similar to what occurs for individuals with other chronic medical conditions (diabetes, COPD, asthma, chronic kidney disease).” – Ludlow, MA*

*“People with diabetes get a diagnosis and are automatically referred to a diabetes health educator. People with Alzheimer’s or a related dementia should have access to a comparable service (dementia care management) that is paid for by insurers including Medicare.” – Los Angeles, CA*

*“Having a system that unifies social workers, counselors, lawyers, etc., under a comprehensive Alzheimer’s family support system would greatly reduce this pressure for families dealing with Alzheimer’s.” – Chico, CA*

## poor dementia care



*“The National Alzheimer’s Plan must address the need for a new system of care coordination for Alzheimer’s families. This could be implemented...with care coordination specialists who assist the patient/caregivers in navigating the health care system and identifying resources in their community, such as respite care, reputable home health services and long-term care options.” – Ashburn, VA*

Another crucial part of the care process for people with Alzheimer’s disease is effective communication between people with the disease, caregivers and health care providers. Many spoke of poor communication experiences with their health care providers, describing them as haphazard or insensitive at times. Others described them as apathetic or even “nihilistic,” leading many to believe their health care providers and the health care system were content to let their Alzheimer’s care slide unless they aggressively advocated on their own behalf.

*“I can’t get the help from the doctors I need. The family doctor laughs and jokes and has a good time with my husband when he’s there but doesn’t answer the questions that I need help with.” – Traverse City, MI*

*“My husband was originally diagnosed with neuropathy. After many more visits with different doctors, my husband received an Alzheimer’s diagnosis. I received no help or information from any of the doctors or referrals to organizations that could help. My pet peeve is that when I took him to all these professionals, they kept saying there was nothing they could do.” – Salisbury, MD*

*“In my opinion the health care professionals today and yesterday have no EMPATHY for us. ‘Get ’em in, get ’em out’ is the attitude I encountered.” – Hampton Falls, NH*

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*“When she is asked a question, they will go with her answer. My mother’s ability to process and reason are no longer there...On the flip side to this, it’s difficult when you sit with a doctor, and **they act as though she is not there at all.**” – Lake Grove, NY*

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These poor experiences led some participants to conclude that health clinicians are generally ill-equipped to address Alzheimer’s disease. They expressed concerns that health professionals were not knowledgeable about Alzheimer’s — how to detect or diagnose it, or how to help people living with it. They described the lack of education as the cause for missteps and insensitivity toward those living with Alzheimer’s and called for more specialized training on an ongoing basis. Indeed, many medical education programs lack sufficient training on Alzheimer’s and dementia.



## poor dementia care



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*“Too many family **doctors** are **fumbling their way through care** and are not adequately equipped to treat these patients.” – Voorhees, NJ*

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*“Most health care professionals are not trained to deal with an Alzheimer’s patient, which creates hardship for both the caregiver and the medical professionals, and may place the patient at risk (such as relying on the patient for descriptions of pain or feelings, when they may not be capable of such expression any longer).” – Mechanicsburg, PA*

*“I feel that it should be required that nursing schools and medical schools provide a specific number of hours within their curriculum prior to graduation. I also feel that the various state boards and nursing and medical boards should require continuing education requirements updates (CEUs) every 10 years. Kentucky currently requires this on both AIDS and domestic violence updates, and adding an Alzheimer’s disease update would make sense.” – Hyden, KY*

*“We need to better train more service providers to understand how to handle the disease in a caring way. One doctor yelled at me in a very condescending way for asking so many questions; another shuffled my mother out the door without helping us figure out what the next steps should be.” – Roseville, CA*

*“...I am appalled at the number of doctors who have no bedside manner or true understanding of this disease. We have no training requirement for nurses other than a brief overview but no hands-on caregiving instruction. We have NO training for direct care staff unless an agency decides to train their own staff.” – Fort Mill, SC*

The challenge of finding adequately trained care extends to institutional care settings, which often meet the non-medical needs of people with Alzheimer’s, such as needed supervision and assistance with activities of daily living. An overwhelming number of people who have experiences with care facilities commented on the need for appropriate training and education in these settings. Many expressed frustration with the level of knowledge care providers demonstrated in caring for loved ones with Alzheimer’s disease.

*“My greatest frustration is the lack of training for some nurses and aides in nursing homes dealing with Alzheimer’s and dementia patients. I don’t know how many times I have been told if my dad wants a drink or snack, all he has to do is ask. We keep candy near him because he was always a snacker, but we get told when he wants some, ‘All he needs to do is ask.’ People with Alzheimer’s and dementia don’t remember things five minutes after you tell them.” – Fayette, OH*

## poor dementia care

*“I could give many examples of the difficulties and challenges we have encountered, but it boils down to people with dementia have unique needs and caregivers and facility administrators need to have comprehensive training. Meeting state guidelines of eight hours of training just is totally inadequate.”*

– Fort Wayne, IN

*“Workers need to be trained on taking care of an Alzheimer’s patient better, too. My father was hit by a nurse’s aide (who was later dismissed) because he would not answer her. He was not able to speak anymore.”* – Matthews, NC

Finding and accessing appropriate dementia care is often even more difficult in rural areas. People living with Alzheimer’s and residing in rural areas typically have limited options when seeking local expertise in cognitive impairment. They have to choose between long commutes to urban areas to find knowledgeable physicians, going without or moving their homes closer to the help they need. Those living in rural areas commented on the need for closer, knowledgeable access to health care and appropriate care services.

*“Lack of specialists, such as neurologist and geriatric psychiatrists, affects the ability of people to be diagnosed in New Mexico. Of the 33 counties in New Mexico, only eight counties have a neurologist.”* – Santa Fe, NM

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***“I live in Spring Hill, TN and have to drive to St. Louis, MO for a physician that treats Alzheimer’s. They need to introduce special incentives for physicians and nurses to specialize in this disease.”***

– Spring Hill, TN

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*“We need a community of aging and dementia specialists and caretakers within easy reach of our homes.”* – Pella, IA

*“In rural areas, a gerontologist is usually not available, and travel is involved in seeing a specialist. Most general practice doctors are not well versed in treating Alzheimer’s disease.”*  
– Jonesboro, AR

## inadequate treatments



One of the most pronounced concerns among participants in the public input process was the fact that there are currently no drugs or interventions available that prevent, stop or slow the progression of Alzheimer's disease. At best, some prescriptions may lessen symptoms for a period of time, but none alter the underlying course of the disease. Some participants acknowledged that prescription medications currently on the market for Alzheimer's disease, such as cholinesterase inhibitors and memantine, helped to address symptoms of the disease for a limited time. Others, though, said these drugs have no apparent effect.

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*"Treatments for Alzheimer's disease? **WHAT treatments?** This is the forgotten disease, literally. You hear about support for every other disease but Alzheimer's." – Red Bank, NJ*

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*"Treatment is a dilemma when the few available medications are for the most part ineffective. Or, if they are effective, there's no way of knowing whether the patient would be in a more advanced stage without them." – Chesterfield, MO*

*"Current treatments are largely ineffective, as once someone has been diagnosed, it's already too late for available medications to do any good. New treatments and medications should be a top priority." – Newtown, CT*

*"Greatest challenge and frustration is that Namenda, Aricept and other drugs prescribed for Alzheimer's are priced so very high and don't seem to accomplish anything. There needs to be extensive research done on the utility value of these drugs and research to see if something can be developed that will have a positive effect in slowing down this disease or even reversing it." – Beaufort, SC*

*"There were countless medications to treat Mom's cancer. There were also many treatment options to deal with any side effects caused by the medications. Each time we visited her oncologist, the doctor had new research results and even more options to try. My dad had Alzheimer's for 16 years. During that entire time, there were only two medications he could try. In both cases, it was questionable if they did any good at all. There were no other options." – Sheboygan, WI*

The absence of disease-modifying treatments is a deep frustration shared in the Alzheimer's community, but additional comments indicate a need to also review the limitations of available behavior-modifying therapies and non-pharmaceutical interventions. Many participants stated that treatments to address changes in behavior such as depression, aggression and sleep disturbances demonstrate limited effectiveness, and are often the most stressful part of caring for an individual with Alzheimer's.

## inadequate treatments

*“New behavior medications need to be developed to work in an Alzheimer’s brain.” – Schertz, TX*

*“We need help treating aggression, depression and agitation in Alzheimer’s patients.” – Grayslake, IL*

*“Many medications used to control symptoms have adverse side effects, which are often worse than the behavioral problems of Alzheimer’s disease.” – Salem, VA*

*“I realize behavior is a big issue. I wish there were specific medications for Alzheimer’s patient behavior, not just the major ones that knock them out!” – Elk Point, SD*

Because today’s treatments vary in their effectiveness from individual to individual, prescribing the right treatment can be a challenge. Many commented on the difficulty of finding the right mix of treatments, often going through a number of combinations before finding an optimal mix, if ever. This approach generates stress for the recipient and their family, as well as questions about doctors’ abilities to prescribe appropriate care.

*“...We really felt they were using Dad as an experiment and had no idea if what they prescribed would really help or not. Treatment options, and better communication of them to families afflicted, should be a TOP priority!” – Thousand Oaks, CA*

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*“The distinctive challenge is that the doctors are stumped. **It’s basically a trial-and-error system**, and they just try different drugs to see what works and what doesn’t.” – Simi Valley, CA*

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*“My experience with management of medications for my mother was rather rocky. It was difficult to find a level of medication that worked for her in the management of symptoms, and then coordinating prescriptions between the physician’s office and the medication department of the assisted living facility was troubling at times.” – Forney, TX*

The profound limitations of today’s treatments represent a challenge that participants addressed passionately and consistently. Many said today’s treatments are inadequate, and developing more effective therapies must be a top national priority.



## specific challenges facing diverse communities



The pervasive misunderstanding that Alzheimer's disease is a "normal part of aging" regrettably rings especially true in ethnic and minority populations. Many people who participated in the public input sessions described how a better understanding of the importance of language and cultural beliefs can assist older adults affected by Alzheimer's from these diverse communities.

Among the challenges that ethnic and minority populations face are the lack of awareness and stigma. While these issues exist for many Americans living with Alzheimer's, many participants noted that cultural norms and values can keep members of diverse communities from seeking and obtaining outside assistance. These, in turn, make increasing awareness and delivering services especially difficult among ethnic and minority groups.

*"I lost my mother after six years from Alzheimer's. One of the themes you are hearing tonight is lack of information, especially in my community. Sometimes a disease is just not sexy enough to get attention. There is especially an issue in the aging, poor, lower-class, African-American community that needs help. The lack of information given to the African-American community is not acceptable; we get information after the rest of the state."* – Baltimore, MD

*"[There is an] extreme lack of knowledge, stigma and denial about the disease with everybody, but particularly in the black community!"* – Durham, NC

*"In my personal experience, first of all, we all need to be an advocate! ...Some Latinos are afraid or don't know what to ask."* – Alexandria, VA

*"I tried to start a support group. I know there is a great need, but I only got three people to come. I am trying to find out why African-Americans are afraid to come to support groups."*  
– Baltimore, MD

Another challenge is timely diagnosis. While whites make up the majority of the more than 5 million people with Alzheimer's and other dementias, research shows that African-Americans and Hispanics are at higher risk — potentially because of the higher prevalence among minority groups of possible underlying risk factors such as diabetes and hypertension. Yet, members of these communities are less likely to have a diagnosis and to say that a doctor has told them they have a "memory related disease." In other words, the already large diagnosis gap is even larger among some minority groups. Then, even when individuals from these communities are diagnosed, it is often in the later stages of the disease when they are more cognitively impaired and need additional medical care.

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***"People from diverse ethnic communities are not properly diagnosed because of socio-economic, language and cultural barriers. Early diagnosis and available treatment and care options are helpful for individuals affected with the disease, especially during early-stage. Most interventions and treatment for Alzheimer's disease patients from the Latino community, for example, take place at an advanced stage of the disease process."*** – Philadelphia, PA

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## specific challenges facing diverse communities



Ethnic or cultural differences can also compound barriers to addressing the care needs of those diagnosed with Alzheimer's disease. While it can be challenging for Americans to identify resources on Alzheimer's disease and care management, it can be even more difficult for individuals who face additional challenges accessing the U.S. health care system. It is further complicated if an individual seeking assistance with Alzheimer's cannot communicate concerns with a health care provider or receive critical information because of language barriers. Many individuals who provided input expressed concern for care management of Alzheimer's in immigrant communities or among groups that use English as a second language.

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*"My greatest concern is care and services available for ethnic minorities, especially those in the immigrant communities. Despite a rapid growth of immigrant populations, little is known about the needs of care and services among these populations. Consequently, **little effort has been made to make current dementia care systems more inclusive.**" – Baltimore, MD*

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*"Cognitive decline is accompanied by a growing dependence on others who may or may not be able to provide the care and support needed. This is even truer of immigrant families with limited skills to navigate the health system and aged spouses who may or may not themselves be well enough or savvy enough to provide the support and management."*  
– Washington, DC

*"I would like the plan to address...lack of access to care (screening, diagnosis, treatment, disease management and caregiver support), especially for people from diverse ethnic communities." – Los Angeles, CA*

*"There [is a] need for cultural training and skills in dealing with Alzheimer's. There is a need to get information, support, understanding and plans for care to a very wide audience."*  
– Washington, DC

## specific challenges facing diverse communities

Disparities also persist in the community where many have a difficult time identifying and accessing long-term care services and supports. People with Alzheimer's and their families must often navigate unfamiliar territory, making the need for education, information and supportive services even more critical. Caregivers struggle to find language-appropriate training and education materials, or to step beyond cultural barriers and accept outside help. In addition, home- and community-based services are primarily offered only in English. Ethnic and minority populations affected by younger-onset Alzheimer's also face their own unique issues.

*"My mom passed away from Alzheimer's. We're Hispanic. I don't know if anyone knows, but when you're bilingual, the patient usually regresses back to their native language. And that brought about a problem with placing her in a nursing home. We could not find a nursing home with Spanish-speaking staff." – Chicago, IL*

*"I would like to address the fact that there are not enough advocacy or programs for the non-English-speaking Hispanics; the Hispanic/Latino caregivers are not aware of the information that is out there." – Rochester, AL*

*"My greatest challenge is finding the medical needs and the right and affordable center. My mom doesn't speak very much English; it's hard for me to take her to any of the medical centers in my area." – Parkland, FL*

*"I'm a bilingual care consultant that represents the Latino community for Santa Barbara County. The challenge they have been facing is the lack of neurologists who speak Spanish and the lack of day support facilities. I'm dealing with clients who have been caregivers for many years, and they're exhausted. They don't have money to put their loved ones in a skilled nursing facility." – Santa Barbara, CA*

*"...[There is a need for] assistance with caregiving for the patient, assistance with housework, social and mental support services in Vietnamese, guidance with estate planning, assistance with transportation." – Houston, TX*



*"Alzheimer's disease and dementia patients in [the] advanced stage retain the language they are born with and develop difficulty communicating in the acquired language, including Tagalog and English. It would be helpful if the family, caregiver and friends could be assisted with programs that would also include facilitating communication by using major dialects such as Visayan, Ilocano, Tagalog, etc." – Los Angeles, CA*

*"In our case we realized we're [a] double minority. We are Hispanics, and there's really not programs [that are] culturally sensitive within Illinois that we can go to. In addition to that, there are very few programs for young[er]-onset." – Chicago, IL*

The public input revealed the dramatic lack of culturally appropriate information, services and tools that respect the closely held values and practices of diverse communities, and several participants called for recognizing this additional need when developing solutions to the Alzheimer's crisis. Many people believe that further understanding of how various groups perceive and experience Alzheimer's and the barriers they face will lead to effective development of solutions that contain authentic relevance to these diverse populations.



## specific challenges facing those with younger-onset alzheimer's

In the United States, an estimated 200,000 people have younger-onset Alzheimer's disease (also referred to as early-onset Alzheimer's).<sup>9</sup> Alzheimer's disease is considered younger-onset if individuals are under the age of 65 years when symptoms first appear. According to many who participated in the public input process, age can be a significant barrier to a timely diagnosis, participation in research, financial assistance and use of community services for people living with younger-onset Alzheimer's. This can exacerbate the already difficult circumstances Alzheimer's presents.

For those with younger-onset Alzheimer's disease, obtaining a diagnosis poses special challenges. Because of the individual's younger age and healthy appearance, clinicians often don't consider Alzheimer's as a possible diagnosis. Often times, doctors diagnose a younger individual with depression or attribute Alzheimer's-like symptoms to stress. It is not unusual for individuals in their 30s, 40s and 50s with the disease to receive conflicting diagnoses from different health care professionals and to wait longer for a diagnosis than older individuals. Those affected by younger-onset Alzheimer's describe recognition of the disease in a younger population as a challenge often resulting in a delayed diagnosis.

*"My concern is that 'younger-onset' Alzheimer's is not being recognized. There are many families who are struggling through the middle of their lives with this devastating disease."*

– Fayetteville, PA

*"At the age of 39, I started to experience some difficulties in my life, which were not normal for me. While at first, they were minor, they became more prevalent over the years. It took over 10 years to finally be diagnosed with Alzheimer's disease."*

– Jamison, PA

*"The greatest challenge was convincing any doctor that my husband, at 60, had symptoms of Alzheimer's that needed a diagnosis."* – Mashpee, MA

Individuals with younger-onset Alzheimer's can also have serious problems in the workplace. The key areas affected in individuals with younger-onset Alzheimer's include short-term verbal and visual memory, knowledge of words or concepts, executive function and organization, judgment and decision-making abilities, personality and motivation. Deficiencies or changes in these important areas can often affect workplace performance and professional relationships and, ultimately, will jeopardize their employment. Numerous people expressed concerns that sharing an Alzheimer's diagnosis with an employer would result in a negative impact on employment status or access to an employer-provided health insurance plan. Many individuals with younger-onset Alzheimer's and their caregivers believe that companies would immediately seek to terminate the affected individual.

*"That diagnosis would mean an end to my career. An excuse can always be found when an employer wants to eliminate an employee."* – Poplar Bluff, MO

*"I would like to get some early testing done since this runs in my family. However, I'm afraid that if I am already on the road to full-blown Alzheimer's, if my company found out they would find a way to avoid putting me on disability and fire me instead. I want employment/disability protection for an Alzheimer's early detection."* – New Market, AL

In addition, people living with younger-onset Alzheimer's also have to deal with barriers due to age. For example, many with younger-onset Alzheimer's are anxious to participate in research. However, many existing research studies focus on older populations, specifically excluding younger-onset participants.

*"I'm 15 and last year my dad was officially diagnosed with Alzheimer's. And when we tried to get him into a couple of the studies at universities, they said he was too young. The cutoff was 50 years old, and he's 48."* – Washington, DC

*"I think they should lower the age for clinical trials, since Alzheimer's disease can start at any age."* – Queens, NY

<sup>9</sup> Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures (2011).

## specific challenges facing those with younger-onset alzheimer's

Age is also an obstacle to using community services such as respite care or long-term care facilities. Activities at adult day centers tend to cater to an older demographic and may not match the interests of younger individuals who also require social interaction in a safe environment while their caregivers are away. Similarly, institutional care settings appropriate for active, younger clients are very hard to find. This forces many with younger-onset Alzheimer's into less than ideal living situations. The lack of care services in already ill-equipped communities, coupled with the potential length of time these services may be needed, creates unique challenges for those with younger-onset Alzheimer's.

*"...There are no good programs out there that are geared toward a young person, like a daycare program or therapy that would interest him. All of the programs are for geriatric patients."*

– Tampa, FL

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*"My biggest obstacle for the past three years of taking care of my now 50-year-old sister is her age. We need more programs available for the younger ones affected by this horrible disease. **I am in shock at how many programs turned us away, including housing, daycare, in-home care, etc., because of her age. Apparently my sister is not old enough to have Alzheimer's!**"* – Chester, MA

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*"Finding an adequate facility for patients who have early-onset. They are forced to be placed in nursing homes with patients who are not at the same physical level of energy."*

– Moraga, CA

*"With more and more cases of early-onset diagnosed every day, we need programs that meet a younger person's needs. We need a place they can go to enjoy more youthful activities like playing basketball or listening to Beatles music — activities our generation can relate to."* – Harveys Lake, PA

Perhaps one of the biggest hurdles individuals with younger-onset Alzheimer's face is the cost of care. Like their older counterparts, people living with younger-onset Alzheimer's require financial assistance to cover costs for treatments and long-term care. But unlike those over 65 years, individuals with younger-onset Alzheimer's lose out on some of their prime earning years. They also do not automatically qualify for Medicare and instead have to demonstrate a disability that warrants coverage, then wait two years before receiving Medicare benefits. Many who are affected by younger-onset argue that the diagnosis, and not age, should be the qualification in determining medical assistance.

## specific challenges facing those with younger-onset alzheimer's

*“My wife was diagnosed with early-onset Alzheimer's at age 53 and was not working at the time. She was primarily a housewife for many years so she did not qualify for Social Security Disability Income. Without a long-term care insurance policy which most people don't consider until their early 60s, there is no state or government assistance available for us since she is so young.” – Corinth, TX*

*“If you have a disease that predominantly affects older Americans, you're old enough. No ifs, ands or buts!”  
– Greer, SC*

*“Although often a disease of the elderly, there are active younger (under 65) people also affected. They lose their jobs and health insurance but are too young for Medicare. This diagnosis may make them uninsurable. The medical costs are high, as are the social consequences. Early-onset Alzheimer's individuals may have children at home, still in school. It is heartbreaking for the caregivers at any age, but when young, any dream of a normal retirement with their spouse is gone. Please don't make early-onset people wait two years after diagnosis for Medicare.”  
– St. Paul, MN*

*“Barbara worked and paid Medicare taxes for over 25 years. Because she was a teacher, she paid into the State Teachers Retirement Fund but not into Social Security. Because she was not part of Social Security, she is not eligible for 'disability' coverage from Medicare. However, if she were to live to 65, she would be eligible for Medicare. We occupy a gap in national programs... National policy needs to account for the fact that some folks who play by the rules need and deserve Medicare coverage before they reach the age of 65.” – Dixon, CA*

*“As a caregiver to my husband who recently passed away from early-onset Alzheimer's disease at the age of 58, my biggest challenge was finding assistance in caregiving. Because of my husband's age, we did not qualify for most programs, and we were left to cope on our own.” – Waterville, PA*



One major change has helped those living with younger-onset Alzheimer's and their families obtain some of the relief they desperately need. In an effort to improve and expedite the disability determination process, the Social Security Administration (SSA) added early-onset Alzheimer's disease to its Compassionate Allowance Initiative effective March 2010. The initiative identifies debilitating diseases and medical conditions that meet the SSA's disability standards for Social Security Disability Income (SSDI) or Supplemental Security Income (SSI). Those affected by younger-onset Alzheimer's are often simultaneously faced with the enormous challenges that the disease presents, while undergoing a long disability decision process that is financially and emotionally draining. Inclusion of younger-onset Alzheimer's in the initiative allows for expedited benefit determinations and serves as a trigger to begin the two-year wait for Medicare benefits for those under the age of 65. Family members (e.g., spouses and minor children) may also be eligible for benefits based on the applicant's work record.

## unprepared caregivers



Nearly 15 million Alzheimer's and dementia caregivers in the United States provide 17 billion hours of unpaid care valued at over \$202 billion.<sup>10</sup> The perspective of these unpaid caregivers, who are often family members, was well represented throughout the public input process.

Caregivers described the stress of caregiving as being very high due to the emotional toll and financial burden of providing quality care. This corresponds with recent estimates that the burden borne by Alzheimer's and dementia caregivers resulted in \$7.9 billion in additional health care costs for caregivers in 2010.<sup>11</sup> Long-term care and support for people living with Alzheimer's is demanding, and caregivers often put their own health and well-being at risk in order to provide for their loved ones. However, to continue providing care safely at home, many caregivers said they need help.

Caregivers, including those living with Alzheimer's and caring for themselves, described the challenges of getting information on what to expect with the disease after a diagnosis. Many families that receive a diagnosis leave their doctor's office without adequate preparation. They have unanswered questions on where to learn more about Alzheimer's, what is needed to provide proper care and what steps to take to prepare for the long road ahead. Without appropriate guidance and little to no information, most people have to set out on their own to identify critical services they don't

even know they'll need yet and, for many, have never accessed before. This can be particularly difficult for those in rural areas where resources are limited. Many participants described the difficulties of having to learn to navigate a complex health care system and put together a care plan for a loved one without a road map or guidance.

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*"It's hard enough to help a loved one who is confused when **you are confused yourself** about how best to help them." – Green Bay, WI*

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*"I have been my grandmother's primary caregiver since the age of 15. I gave up everything to take care of my grandmother. I received no help from the government for bills, I received no information about resources. I have struggled with this disease for over five years and am still struggling." – Corinth, MS*

*"We need clear resources to help the caregivers understand the finances, insurance and care implications of working with an affected family member." – Redwood City, CA*

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*"Both my mother and father suffered from broken hip fractures. Every step of the way, I was clued into what the next step was in their recovery. **With Alzheimer's...you are on your own.** No preparation, no support group at the doctor's, no real understanding or sympathy from the medical community except for some good souls here and there." – Davie, FL*

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<sup>10</sup> Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures (2011).

<sup>11</sup> Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures (2011).



## unprepared caregivers



Adding to caregivers' confusion is the unpredictable duration of Alzheimer's disease. There's no foreseeable timeline as to how stages will progress, which makes it difficult for caregivers to know what to expect from day to day and month to month. On average, a person lives with Alzheimer's four to eight years but can live as long as 20 years.<sup>12</sup> The prolonged duration of Alzheimer's places increasingly intense demands on the millions of family members and friends who provide care. Consequently, people living with Alzheimer's disease and their caregivers face a long, challenging road of questions, financial burden and emotional distress.

*"My top concern is wearing out my caregiver (wife). The added stress makes her more vulnerable to illness, depression, etc. The plan needs to address ways to support the caregiver emotionally and physically. Some form of respite."*

– Manhattan Beach, CA

*"Being a full-time caregiver to my mother is difficult because it is so hard to find any spare time to have a life of my own. I desperately need time to rest and socialize with friends. Others have trouble understanding that I am living two separate lives, paying two sets of bills, caring for two lawns, seeing to it that another adult takes her medicine, eats and bathes, and is constantly entertained." – McAlester, OK*

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*"Until a cure is found, or a way to halt the progression of Alzheimer's, **we need to find a way to help the caregivers.** The caregivers are saving us billions of dollars a year by maintaining the person at home, compared to the cost of institutionalizing someone."*

– Waterloo, IA

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*"The state of our economy and increasing aged population place greater demands on multi-generational family members to care for Alzheimer's patients, yet proper education, services and support has not kept up with this growing need."*

– Valley Center, CA

<sup>12</sup> Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures (2011).

## unprepared caregivers

To counter the confusion and stress of dealing with Alzheimer's, people with the disease and their caregivers can benefit from education on Alzheimer's disease. Caregivers shared that trying to face Alzheimer's on their own was extremely challenging and emphasized the importance of being educated about all aspects of the disease. In addition, caregivers and families need education on the types of supportive services available in their communities to assist them in providing care. It was also evident that caregivers expected their physicians and health care providers to provide them with information on where to get additional help.

*"With each stage of care, we need information on what assistance might be available to keep the family member in the least restrictive (and least expensive) care. A central location to get this information that is in an easily understood language would be most helpful." – Omaha, NE*

*"The better prepared you can be, the easier it will be on the caregiver and the loved one. Education is critical. We're not getting enough of it, and the doctors are not helping whatsoever. There needs to be more education to them — they need to learn more about Alzheimer's, how it affects the families. It's a family disease. We're affected greatly by it, much more so than our loved ones even are." – Greer, SC*

*"There should be free counseling for caregivers and family members and free classes to enroll in to learn more about the disease and how to communicate with those with the disease." – Cardiff, CA*

*"Seminars on Alzheimer's disease share so much information with you in such a short time that it is overwhelming and much is forgotten. Up-to-date video series for caregivers should be given out free through the doctor and provided by state or federal government agencies." – Danville, IL*

*"A good guideline about what to expect, how to respond to the patient (even though they are not making sense), being prepared for ongoing stages of deterioration and change over time can better prepare families to work through this disease and not feel so frustrated." – Sharpsburg, GA*



People living with Alzheimer's and their caregivers can also benefit greatly from community services that support in-home care. These include respite care, adult day services and home health aides. While many people, including individuals with Alzheimer's, expressed their desire to stay at home in order to preserve familiar surroundings and independence as long as possible, constraints such as availability and costs can encumber use of these vital services.

*"I am the sole caregiver for my wife, who is in the middle stage of Alzheimer's. I'm 81; it is unsafe and very hard to keep up with her day and night, and I am not able to pay for help. I may be forced to put her in a nursing home or other institution, which I can't afford. Nursing care will cost me and someone else, probably a government agency, a lot of money. I want my wife home and will continue to care for her as long as I am able. I would like to see a program which provides assistance for in-home care, which is certainly less costly for both me and the government than institutionalized care." – Minooka, IL*

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***"My family struggled with the option to keep my father at home. There were options with financial and social support if we were willing to put him in a facility, but this was not his, or our, preference." – Thousand Oaks, CA***

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## ill-equipped communities

Many participants living with Alzheimer's stated that they want to live at home as long as safely possible. However, they described how barriers to accessible and affordable home and community services that support independence and long-term care at home often force those with Alzheimer's into institutional care settings sooner than needed. Many participants commented on the shortfalls found within their own communities and what they need to overcome these barriers.

One of the most frequently mentioned needs to support independence at home is additional home health assistance through private health insurance or Medicare. While Medicare offers in-home health assistance for skilled services such as skilled nursing care or physical therapy, it does not offer assistance for personal care services to help with day-to-day activities. Families contending with Alzheimer's disease that rely on Medicare currently pay out-of-pocket for personal care support at home, which can become very expensive over time. Many respondents described assistance with activities of daily living such as bathing or dressing a loved one as an immediate need, particularly for caregivers who have other full-time commitments such as a job or a family and elderly caregivers who need help with the physical aspects of caregiving.

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***“How do you pick up a 200-pound man? That’s how much my husband weighed. I had to put him in a home when I could no longer move him.”***  
– Sequim, WA

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*“What was not covered at all was the cost of someone to wash and dress them, do cooking and cleaning, etc. This was especially important for my mother, who had to be moved on and off the toilet, cleaned up afterwards, fed because she could no longer feed herself, etc. We needed a non-medical person with them 24/7, and this was not covered by insurance.”*  
– Chicago, IL

According to participants, another major need is affordable and accessible respite care. Caregiving at home is an around-the-clock job. Respite care provides a safe, temporary break from daily caregiving responsibilities and can strengthen a caregiver's ability to continue caring for a loved one with Alzheimer's at home. Respite care services can be brought in the home or found outside the home in the form of adult day centers, which offer social interaction, structured activities and other services for individuals with Alzheimer's who might otherwise be confined to the safety of their homes and isolated for periods of time.

Unfortunately, respite services such as in-home respite or adult day centers are often quite expensive, especially over time, and most people must pay out-of-pocket or go without since many insurance programs, including Medicare, do not cover respite services.<sup>13</sup> This problem is even more acute in rural communities where respite care may not be available at all.

*“One of my problems is that I desperately need respite care. This is very expensive. I need to be able to have a break once a month from the day-to-day overwhelming duties.”*  
– Encinitas, CA

*“My husband has had Alzheimer's for seven years. He's 76, I'm 74, and I'm doing it at home by myself. The one thing I need is time to do shopping. They need a place that we can take them for a few hours; there is no place where I live. I have to take him everywhere I go, but it is getting too hard to do it. He is in the last stage.”* – Trout Run, PA

<sup>13</sup> Under Medicare, respite care is only offered as a service under the Part A hospice benefit.



## ill-equipped communities

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*“Providing round-the-clock care to someone with this disease is very challenging and **the longer they have the disease, the more challenging their care becomes.** Caregivers need a break from that scenario frequently. Without adequate time away, every level of care starts to break down.”*

*– Jonesboro, AR*

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*“Sussex County, Del., is very rural but has become a retirement community with retirees that move here and have no family in the area. When one develops Alzheimer’s, community services are needed. Affordable respite care and transportation are the main issues for those in this area.” – Georgetown, DE*

*“Our town has no adult daycare service, and the closest is 25 miles away, simply too inconvenient to use. There is an assisted living facility eight miles away that advertises daycare services; however, they do not have dedicated staff or services for daycare clients who would get no attention or stimulation for two to three hours at a time.” – Waterloo, IL*

*“In small cities like ours, there is no place for Alzheimer’s patients to meet together as a group and receive attention from people who know how to socialize with Alzheimer’s patients.” – Pinetop, AZ*

*“When I cared for my grandma it was most frustrating to know that we couldn’t afford to send her to a place where she could be cared for properly during the day and still come home at night.” – Woodbridge, NJ*



When individuals living with Alzheimer’s and their families cannot access community services or such services no longer sufficiently meet their needs, many are forced to transition from their homes into institutional care settings such as skilled nursing facilities or Alzheimer’s special care units. Many communities lack transitional housing that bridges the gap between those who still want to maintain independence and do not yet require daily skilled nursing care.

*“There are very few options for any type of transition housing. As soon as you say ‘Alzheimer’s,’ you get sent to a nursing home with a lock-down ward.” – Kansas City, MO*

*“Please address the need for more Alzheimer’s-focused nursing homes/assisted living facilities for people who are not physically in poor health but need constant supervision and activities to keep them busy. They can’t be expected to lie around in bed all day at regular nursing homes when they are mobile and have no reason to lead a sedentary lifestyle.” – St. Louis, MO*

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*“We now have her in an assisted living facility for the last two years, but **could have kept her with us longer if we could have found a daycare facility.**” – Austin, TX*

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## ill-equipped communities

Unfortunately many care facilities in the community are not prepared to manage the individualized demands of Alzheimer's. They struggle to handle the growing number of people with dementia and their intensive needs, and they do not have enough adequately trained staff knowledgeable about Alzheimer's and how to care for people who have it. Caregivers also described experiences with facilities that said they provided dementia-specific care services but fell short of expectations, leaving family members feeling exasperated. Participants particularly singled out facilities that are not prepared to handle some of the behavioral issues that can accompany Alzheimer's. Anxious, aggressive or repetitive reactions can lead to misunderstanding and tension for the person with Alzheimer's, and care facilities with inadequately trained staff are unable to address these behaviors appropriately.

*"The staff in the nursing home is rushed to take care of many patients, they don't get paid very well, and for the majority it is just a job, not a vocation. They clock in and clock out. Weekends are just a skeleton staff. Patients are not intentionally mistreated but they do not get individual care, and in many cases they are ignored."* – Middletown, DE

*"It was a major battle with the nursing home to take my wife when she needed care. Most facilities have a waiting period of six months to a year."* – New Braunfels, TX

*"The caregivers really liked Mom and did their best to attend to her needs. They just had too many patients per person to give the level of care needed."* – Independence, MO

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*"I have noticed that many nursing homes will turn Alzheimer's patients away **as they do not have the resources or manpower to handle it.**"*

*– Nevada City, CA*

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*"I would also like to see some type of rules and regulations be put in place that govern when a 'nursing home' can state they care or specialize or are experienced in Alzheimer's."*  
– Creve Coeur, MO

*"Once he was better physically he developed habits typical of the disease: pacing, day/night confusion, agitation. My mother and I had assumed that Alzheimer's units would be the very places equipped to deal with these symptoms. We were shocked to find that these very facilities would not accept my dad as a resident, nor would any other nursing homes in our immediate area. We had no option but to send him to a geriatric behavioral unit of a hospital 90 minutes away."* – Bloomington, IN

*"I am also appalled that many patients suffering from dementia in long-term care facilities end up in the psych wards of hospitals under what we call the Baker Act here in Florida. They are said to be a danger to themselves or others when often they are merely acting out because of the unconscionable treatment they are receiving, or they are trying to escape from what they perceive to be imprisonment."* – DeLand, FL

## ill-equipped communities

*“Many people with Alzheimer’s disease develop problem behaviors in the course of the disease. ... Many senior facilities refuse to accept the senior with behavior disturbances because of the risks involved.” – Mesquite, TX*

*“Even though the majority of people with Alzheimer’s have problems with irritability, physical and/or verbal outbursts and can be aggressive with other residents and staff, facilities report it to family members as if we could sit our loved one down and convince them not to ‘act up’; care providers for residents are asked to medicate residents to prevent or stop these incidents.”  
– Fort Wayne, IN*

With the number of individuals affected by Alzheimer’s projected to grow to as many as 16 million by the middle of the century, this expanding population will have profound implications for communities that are already having difficulties addressing the multiple and complex challenges that Alzheimer’s poses to individuals, families and community and state programs.

As Alzheimer’s disease progresses to late stages and end-of-life care is needed, many individuals turn to hospice care. Hospice is a covered Medicare benefit that has proven invaluable to individuals and their families at the end of life. Hospice care provides comfort, care and support services for people with terminal illnesses in their home or in an institutional care facility. Families affected by Alzheimer’s that were able to find and access hospice services consider it vital, and many requested access to hospice care and its holistic services before late stage or end-of-life care is required.

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### ***“Hospice was a godsend.”***

*– Lee’s Summit, MO*

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*“The only time our family felt any relief in the six-year care of my mother was when, in the last month of her life, we qualified for the hospice program.” – Rancho Cordova, CA*



*“Hospice of Medina County has been very helpful in assuring that my mother receives appropriate care in the skilled nursing facility. The resources and support they provide to our family have been invaluable.” – Cleveland, OH*

*“Hospice has been so wonderful to me and most importantly my sweet mom. They have nurses, caregivers, chaplains and social workers that check on her every week. I get a call from her nurse every week and she tells me how Mom is doing.”  
– Arlington, VA*

*“Once Alzheimer’s patients reach the mid-late stages of the disease, hospice care should be discussed and offered. We LOVED the Hospice of Northeastern Illinois. They made the last week of Mom’s life comfortable and peaceful. I wish we would have been able to move her into hospice sooner.”  
– Algonquin, IL*

*“My mom is on hospice, which is extremely helpful to my family.” – Cooper City, FL*

*“We have had assistance from Hospice of the East Bay (Northern California) for about six months. Their service to my wife, Mary Ann (who has Alzheimer’s) has been excellent. Their people are very sensitive and caring, which is most important!” – Danville, CA*

## mounting costs of care

One of the biggest challenges for people living with Alzheimer's and their caregivers is the financial burden of care. This includes the costs of treatments, doctor visits, custodial care services, respite services and institutional care. Every stage of the disease has costs associated with it that can become difficult to manage over time. People living with Alzheimer's disease often rely heavily on government programs such as Medicare and Medicaid to mitigate these costs. Unfortunately, too often Medicare and Medicaid are inadequate, and the overwhelming costs of this disease exceed available personal funds, leaving families affected by Alzheimer's in the difficult position of having to balance sufficient care for their loved ones without impoverishing themselves.

Many people simply said they need more help. For example, available treatments to address symptoms of Alzheimer's can be costly, especially for a disease where people live for a number of years. Those who have been paying for current treatments find these costs can become totally unaffordable over time. Relief in the Medicare drug benefit coverage gap will come in 2020 when cost-sharing decreases significantly, but for some, relief can't come soon enough.

*"While we have always worked hard to provide our own insurance coverage, we were really in a bind last year when he 'hit the donut hole' in our coverage. Neither of us ever worked anywhere where there was a pension plan and we worked hard to look out for our own future by investing what we could. We hate now to see our meager savings dwindle because of the cost of medication." – Courtland, VA*



*"One of my biggest frustrations is the cost of the Alzheimer's drugs. Alzheimer's is the MOST devastating of all diseases in my experience. And to be essentially punished by the exorbitant cost of the drugs to fight it is totally uncalled for." – Sallisaw, OK*

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*"I was diagnosed at 55. One medication copay is \$234/month, but I lose my COBRA coverage in 60 days. **What will I do then?**" – Reminderville, OH*

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*"Medication is very expensive if you're paying out of pocket and only have Medicare." – Bakersfield, CA*



## mounting costs of care



Those who have to deal with the costs of treatments also have to deal with the costs of care at home. And like treatments, many services to support in-home care require paying a large portion of it out of pocket. An overwhelming number of people who live at home or maintain in-home care requested additional home health services through Medicare. Medicare currently offers in-home health coverage to homebound individuals for skilled services such as skilled nursing care or physical therapy. However, families affected by Alzheimer's disease currently must pay out of pocket for personal care support at home or in a nursing facility, the costs of which mount over time.

Many people described assistance with custodial care such as bathing or dressing a loved one as an immediate need, particularly for caregivers who have other full-time commitments or who need help with the physical aspects of caregiving.

*“Most insurance won’t cover just custodial care and personal care assistance, but this is what is disabling and killing the caregivers of these patients. Even long-term health care benefits cover this only partially, and most people don’t have it due to the prohibitive costs of the plans available.”*  
– Laguna Hills, CA

*“I would like to see improvements in the way Medicare funds home health care, so that families can remain together and in familiar surroundings longer.”* – New York, NY

*“She doesn’t need ‘nursing’ care for any particular illness. She needs support for activities of daily living, basic needs like bathing, food preparation, housekeeping. These things are quite expensive [and] not covered under insurance.”* – Bensalem, PA

*“Families need help with ADLs [activities of daily living], e.g., bathing assistance, incontinence assistance. It takes two adults to change Mom at this point, and even with two people, it is extremely difficult physically.”* – Grand Junction, CO

*“I have a mother with Alzheimer’s, and one of my frustrations is that since she is otherwise physically healthy she does not qualify for financial assistance for the assisted living facility she is in. She may not need medical assistance, but she does need 24-hour supervision. . . . So besides the lease on her room which includes senior activities, we also pay for 24-hour home care. Medicare does not cover any of this.”* – Gaylord, MI

The prolonged duration of Alzheimer's places increasingly intense demands on the millions of family members and friends who provide care. Over time, many families become too overwhelmed with the physical and emotional requirements of providing care and are forced to seek the type of round-the-clock care that can only be found in institutional facilities. These families learn that costs for these types of facilities can quickly deplete financial resources as the annual average cost of a nursing home for a person with dementia was over \$70,000,<sup>14</sup> an amount few families are able to afford. Medicaid is the only federal program that covers long nursing home stays, but beneficiaries must be financially and medically eligible to receive coverage. Many people commented on the challenge of finding affordable institutional care that adequately meets the needs of individuals with Alzheimer's.

<sup>14</sup> Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures (2011).



## mounting costs of care



*“It cost us \$10,000 per month for both of our mothers’ care in a nursing home years ago, plus medications, but what are you going to do? It’s your mom.” – Colorado Springs, CO*

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*“He has to pay \$6,000 per month to keep her there, which is more than he makes... I am watching a man who has worked hard for everything his entire life and paid taxes **sell off his possessions little by little to pay for his wife’s care.**” – Cleveland, OH*

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*“I looked into nursing homes. There was only one in the city of Los Angeles strictly dedicated to Alzheimer’s and dementia. At any nursing home, she would not receive the one-on-one care she so desperately needed, and with all the levels of care she required, it would have cost us \$9,000 a month. Who can afford that? Definitely not most Americans.”  
– Los Angeles, CA*

*“It is unconscionable to see quality care based on the families’ ability to pay. Families who have financial resources will get better treatment than the poor under today’s standards. Poor families who cannot afford private nurses or private nursing homes are relegated to state care where every level of care is substandard. The cost to families wanting quality care for their loved one will bankrupt a middle-class family, make them sell their home and all of their assets and have nothing left.”*

*– Nashville, TN*

Government programs, such as Medicaid or veterans benefits, provide additional avenues of financial assistance. However, people affected by Alzheimer’s disease and their caregivers face barriers in meeting eligibility criteria. For example, many people who seek Medicaid assistance to help with the costs of caregiving commented heavily on the coverage gap due to income constraints. The strict guidelines for Medicaid require individuals with Alzheimer’s to “spend down” most their income, assets or both in order to qualify for assistance (specific guidelines vary by state).

*“My dad, 72 years old, is a shell of who he once was. He had been diagnosed over nine years ago, and my mom has been taking care of him 24/7 since then. She physically cannot do it anymore. ...She feels her only option is to go on Medicaid and place him in an Alzheimer’s facility, and the amount of money Medicaid will take from her and allow her to live on is BELOW the poverty level. Not only does my mom have to endure a sad, sad situation of her spouse of 50 years not knowing who she is, she also must lose all she has to have him taken care of.” – Naperville, IL*

*“Spouses should not be burdened with the ‘spend-down’ to care for their loved one through Medicaid after they exhausted their financial resources. How are they supposed to live and take care of themselves?” – Orland Park, IL*

## mounting costs of care



*“I applied for Medicaid for my mother, age 89, with Alzheimer’s about a month ago. She was told that because of a little over \$2,000 in life insurance that she doesn’t qualify.”*  
– Indianapolis IN

*“I am the sole caretaker of two parents with Alzheimer’s. My ‘job’ has been 24/7 for the last three years. I have had to give up my job, my savings are gone, and I’ve had to declare bankruptcy. My parents are living on Social Security, so that is three of us stretching a budget that is extremely small. **They are \$50 over Medicaid guidelines.**”*

– Aurora, CO

*“...There needs to be more publicly funded options for those who cannot afford expensive facilities or costly adult daycare centers and therefore feel trapped into caring for the Alzheimer’s patient at home, at a cost to other family members. Unfortunately, the reverse is happening, as federal and state budgets ax funding for these programs to make up for revenue losses in the past few years. It’s incredibly short-sighted to not understand that the people who are most hurt by the lack of public assistance are the backbone of our nation: the low-income and middle-class workers who cannot sustain this level of caregiving.”* – San Diego, CA

*“My father runs his own business and was unable to stay at home to give Mom the 24-hour care that she desperately needed as her Alzheimer’s progressed. I now see a man who has worked hard his entire life and been a loving father and husband faced with the following options: 1) divorce his wife of 35 years so that she can qualify for Medicaid; 2) liquidate his (small) retirement fund and sell his possessions little by little to pay for her \$6,000/month nursing home bills; or 3) liquidate all of his assets to allow my mother to qualify for Medicaid as his spouse. It sickens me that people work their whole lives to provide for their families and are faced with these options when a loved one falls ill. ...What does it say about a country where it is more beneficial to divorce your spouse of 35 years to pay for her care than it is to be there for her when she needs you most?”*  
– Cleveland, OH

## mounting costs of care

The lengthy and complicated process for requesting government assistance can be a barrier to access as well. Many people commented on the frustration of filling out forms and waiting for a response.

*“We tried to get [help from] the Veterans Administration (Dad was a WWII war veteran), but the process took over 18 months. When he died we still had no answer from them, but they did notify us that since he was deceased, the file was immediately closed with no resolution.”*  
– Thousand Oaks, CA

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*“You have to go through so much red tape on the state level. Information being lost, then [you] must try and file for the same help all over again, and sometimes that help never comes through.”* – Gary, IN

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*“While the Veterans Administration offers quite extensive help for home-bound patients, the process of applying for this help is rigorous and complicated... Getting help placed in the home takes considerable time, and when the patient is at poverty level, there is no help until the grants kick in, which can take years.”* – Glastonbury, CT

Despite the financial strain and barriers to access, some have navigated this process successfully and shared their thoughts on programs that helped to alleviate the burden of caregiving and keep loved ones with Alzheimer’s at home — programs that could help others if they were expanded. However, in light of the current economic environment, the future of these programs is in doubt.



*“Cost of SNF [skilled nursing facilities] and ALF [assisted living facilities] is more than if you provide care at home with programs like the CDC Plus program. With the CDC Plus, a representative can hire caregivers at a lower cost and funds are from the Medicaid waiver.”* – Lakeland, FL

*“In Alameda County California, the IHSS program has allowed me to care for my mother and keep her in her home of 60 years.”* – Hayward, CA

*“The programs that helped me the most for my mother was a grant that provided some funds for respite for me.”*  
– Bucklin, KS

*“Also relied on the local adult daycare program; once she got started she LOVED it! That helped me take breaks during the day to recoup and prepare for her return for the afternoon and evening.”* – Apache Junction, AZ

# an agenda to overcome alzheimer's

The leading Alzheimer's challenges that emerged from the Alzheimer's Association's public input process offer a policy framework for evaluating the country's first National Alzheimer's Plan. A successful Alzheimer's plan will make meaningful advances toward overcoming each of the challenges identified by the more than 42,000 Americans who participated in this process.

Fortunately, each of the challenges highlighted in this report can be meaningfully addressed through federal policy. The following are the most important ways the National Alzheimer's Plan can accomplish this objective, featuring policy recommendations that emerged from the public input.

## ***To address a lack of public awareness:***

The National Alzheimer's Plan should launch a nationwide Alzheimer's awareness campaign designed to increase awareness of the disease, promote early detection and diagnosis, and promote available services.

## ***To overcome insufficient research funding:***

The National Alzheimer's Plan should, as a leading priority, immediately increase annual Alzheimer's funding to \$2 billion, a level scientists believe can be productively and strategically invested at once in pursuit of Alzheimer's breakthroughs; simultaneously, initiate a process to determine the higher level of annual funding appropriate over the long-term.

## ***To overcome difficulties with diagnosis:***

The National Alzheimer's Plan should encourage health care providers to improve the detection and diagnosis of Alzheimer's and pair each diagnosis with immediate, meaningful care planning and recording of the diagnosis in the patient's medical record.

## ***To overcome poor dementia care:***

The National Alzheimer's Plan should define the elements of quality dementia care, determine the best indicators to measure whether this care is being delivered, and embed these measures throughout the health care system to drive better practice. Emphasis should be placed on improving rates of diagnosis, reducing preventable hospitalizations and encouraging greater care coordination.

## ***To overcome inadequate treatments:***

The National Alzheimer's Plan should recognize Alzheimer's as an unmet medical need within the context of the Food and Drug Administration's accelerated drug review processes, and it should correct any barriers that discourage the aggressive pursuit of preventive and other pre-symptomatic treatments.

# an agenda to overcome alzheimer's

## ***To overcome the specific challenges facing diverse communities:***

The National Alzheimer's Plan should ensure that every relevant Federal effort to address health disparities recognizes the tremendous challenges that Alzheimer's and other dementias pose to diverse communities, and incorporate specific objectives, strategies and actions within these efforts to address them.

## ***To overcome the specific challenges facing those with younger-onset Alzheimer's:***

The National Alzheimer's Plan should prioritize an assessment of the size of the younger-onset (under age 65) Alzheimer's community, ensure full and equal access for these individuals to all Alzheimer's programs and supports available to older Americans with Alzheimer's, and address the particular needs of this population when programs designed for older Americans are not appropriate.

## ***To support unprepared caregivers:***

The National Alzheimer's Plan should widely deploy Alzheimer's caregiver support services that are culturally sensitive to diverse audiences and integrate elements from the best evidence-based caregiver interventions, such as caregiver consultations to identify the needs in each individual situation.

## ***To overcome ill-equipped communities:***

The National Alzheimer's Plan should call for the creation of demonstration projects under Medicare to evaluate the outcomes of expanding adult day health services for those with Alzheimer's and home health care for the purpose of preserving the abilities and independence of persons with dementia.

## ***To overcome mounting costs:***

The National Alzheimer's Plan should, in addition to cost reductions achieved through the above recommendations, address a major driver of costs to the federal and to state governments, as well as to American families, by equipping families to keep persons with dementia at home longer through access to custodial care services without having to reduce their savings to the point of becoming Medicaid eligible.

While by no means an exhaustive or detailed list of the steps that should be taken immediately to overcome the Alzheimer's crisis, these recommendations mark a transformational and achievable start. On behalf of thousands of Americans who contributed to this process and the millions more they ably represented, we urge the Obama administration and Congress to move swiftly to implement these critical actions.







The Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease.®

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