Understanding Younger-Onset (Early-Onset) Alzheimer’s Disease

Olive Branch, Mississippi
August 15, 2012

Monica Moreno
Director, Early-Stage Initiatives

Dr. Ron Grant
Former National Early-Stage Advisor
Overview

• Impact of Alzheimer’s disease on the US
• Understanding Dementia
• The Face of Alzheimer’s Disease
• Advocacy Initiatives
• Early-Stage Programs and Services
What We Know

What Americans report . . .

• Relatively high concern
• Most feared disease by older women
• 90-plus percent know someone with Alzheimer’s

What Americans “know” . . .

• “Just a little memory loss”
• “Only really old people”
• “It’s not that bad – the person doesn’t know”
• “It’s not like it’s fatal”
ONE IN EIGHT OLDER AMERICANS HAS ALZHEIMER'S DISEASE. ALZHEIMER'S DISEASE IS THE SIXTH-LEADING CAUSE OF DEATH IN THE UNITED STATES. OVER 15 MILLION AMERICANS PROVIDE UNPAID CARE FOR A PERSON WITH Alzheimer's OR OTHER DEMENTIAS. PAYMENTS FOR CARE ARE ESTIMATED TO BE $200 BILLION IN 2012.

- 6th leading cause of death in the U.S.
- Over 5 million Americans live with Alzheimer’s
- Every 68 seconds someone in America develops Alzheimer’s
- Baby boomers are entering the age of greatest risk
- More than 15 million caregivers
People with Alzheimer’s Disease and Other Dementias Who Live Alone

At least 800,000 Americans with Alzheimer’s disease live alone

- Increased risk of
  - Missed or delayed diagnosis
  - Nursing home placement
  - Falls
  - Self neglect

- Wandering away from home
- Social isolation and loneliness
- Untreated medical conditions
- Fatal injuries
Alzheimer’s and Mortality

• More Americans suffer from Alzheimer's disease than breast cancer and prostate cancer combined

• Only cause of death among the top 10 in America without a way to prevent, cure or even slow its progression
The Alzheimer’s Caregiver

- Nearly 15 million people provide unpaid care for Alzheimer’s or other dementias
  - 77% of caregivers were between the ages of 35 – 64 years
  - 60% are women

- Eighty percent of care provided at home is delivered by family caregivers
  - 44 percent are employed full or part time
  - 65 percent said they had to go in late, leave early or take time off
  - 20 percent had to take a leave of absence
## Number of People Aged 65 and Older with Alzheimer’s by Age

<table>
<thead>
<tr>
<th>Year</th>
<th>65–74</th>
<th>75–84</th>
<th>85+</th>
<th>Total</th>
<th>% change from 2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000</td>
<td>3,400</td>
<td>26,000</td>
<td>22,000</td>
<td>51,000</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td>3,200</td>
<td>26,000</td>
<td>24,000</td>
<td>53,000</td>
<td>4%</td>
</tr>
<tr>
<td>2020</td>
<td>4,100</td>
<td>28,000</td>
<td>26,000</td>
<td>58,000</td>
<td>14%</td>
</tr>
<tr>
<td>2025</td>
<td>4,700</td>
<td>33,000</td>
<td>27,000</td>
<td>65,000</td>
<td>27%</td>
</tr>
</tbody>
</table>
MISSISSIPPI
ALZHEIMER’S STATISTICS

Percentage Change in Number with Alzheimer’s Disease Compared to 2000

Cognitive Impairment in Nursing Home Residents, 2009

Total Nursing Home Residents 29,306

Level of Cognitive Impairment
- severe/moderate: 43%
- mild/very mild: 23%
- none: 29%
Caring for people with Alzheimer’s or other dementias will cost the United States $200 billion in 2012, including $140 billion paid by Medicare and Medicaid.

*Data are in 2012 dollars.

Source: Alzheimer’s Association 2012 Alzheimer’s Disease Facts and Figures
Why is Alzheimer’s such a cost driver?

- Nearly 30% of people with Alzheimer’s or another dementia are on both Medicare and Medicaid.

- Most people with Alzheimer’s have 1 or more other serious chronic conditions, and dementia complicates the management of other conditions.

- A senior with diabetes and Alzheimer’s costs Medicare 81% more than one with diabetes and Alzheimer’s and an older person with Alzheimer’s and cancer costs Medicare 53% more than one with cancer but no Alzheimer’s.
The Current Trajectory

The diagram shows the projected increase in costs from 2010 to 2050, with the following milestones:

- 2010: $172 billion
- 2015: $202 billion
- 2020: $241 billion
- 2025: $307 billion
- 2030: $408 billion
- 2035: $547 billion
- 2040: $717 billion
- 2045: $906 billion
- 2050: $1.078 trillion

The chart indicates a consistent upward trend, with the cost increasing by approximately $122 billion each year, culminating in a projected $1.078 trillion by 2050.
Understanding Dementia

Dementia

- Reversible dementias
- Vascular dementia
- Frontotemporal dementia
- Lewy body disease
- Alzheimer's disease
Irreversible Types of Dementia

- Alzheimer’s disease: the most common type of dementia
- Up to 80% of people with dementia have Alzheimer’s disease
What is Alzheimer’s disease?

Alzheimer’s disease

- Is a brain disorder
- Is a progressive disease
- Is the most common form of dementia
- Is fatal
How the Brain Works

• There are 100 billion nerve cells, or neurons, creating a branching network.
• Signals traveling through the neuron forest form memories, thoughts and feelings.
• Alzheimer’s destroys neurons.
Neurons Affected by Alzheimer’s

Plaques

Tangles

Alzheimer cells

Healthy cells
Major Risk Factors

- Age
- Higher incidence in women
- Family history
- Correlation between Down syndrome and Alzheimer’s disease
Progression of Alzheimer’s

On average

- people live four to eight years after diagnosis
- 40 percent of a person’s years with Alzheimer’s are spent in the most severe stage of the disease – longer than any other stage

• 75 percent of people with Alzheimer’s will be admitted to a nursing home by age 80
  - 4% of the general population will be admitted to a nursing home by age 80
The Face of Younger-Onset Alzheimer’s Disease

Living with Younger-Onset Alzheimer’s Disease
Younger-Onset (Early-Onset) Alzheimer’s Disease

Definition:
Refers to Alzheimer’s affecting people who are under the age of 65

People who have younger-onset dementia may be in any stage of dementia

– Early
– Middle
– Late
Causes of Younger-Onset Alzheimer’s

• Most people with younger-onset have the common type of Alzheimer’s, which is not directly linked to genes.
  – Doctors do not know why symptoms appear at an unusually young age in these cases.

Genetic Link

• In a few hundred families worldwide, scientists have found several rare genes that directly cause Alzheimer’s.
  – People who inherit these rare genes tend to develop symptoms in their 30s, 40s and 50s.
Impact of Younger-Onset Alzheimer’s Disease

- Employment issues
- Financial
  - change in plans for the future
  - cost of living
- Health insurance coverage
- Cost of care
  - High out of pocket expenditures for medical care
- Lack of community service programs
- Impact on family
Typical age-related changes involve:

- Making a bad decision once in a while
- Missing an occasional monthly payment
- Forgetting which day it is and remembering later
- Sometimes forgetting which word to use
- Losing things from time to time
Problematic Changes

Changes indicating the need for a doctor’s visit:

• Consistent poor judgment and decision making
• Loss of an ability to manage money
• Inability to keep track of the date or the season
• Difficulty having a conversation
• Misplacing things and loss of the ability to retrace steps to find them
• Trouble with visual and spatial relationships
• Difficulty with executive function
Getting a Diagnosis

• Health care providers generally don’t look for Alzheimer's disease in younger people
• Symptoms may be incorrectly attributed to stress
• May receive conflicting diagnoses
• Can be long and frustrating process
• Importance of
  – Early detection
  – Linking to supportive services and resources
After Diagnosis

• Experience range of emotions
• Sense of loss in abilities
• Loss of identity
• Change in relationships
• Sharing the diagnosis with others
  – Stigma of the disease
After Diagnosis

• Get educated
• Know what to expect
• Plan for the future
• Find peer support
Living Your Best Life With Alzheimer’s Disease

• Develop daily coping strategies
• Spirituality and inner peace
• Cope with changes
• Raise your voice
• Stay engaged
Meeting the Needs of Individuals with Younger-Onset Alzheimer’s:

Advocacy Initiatives: Where are we Now?
National Alzheimer’s Project Act

• Create a national strategic plan to overcome the Alzheimer’s disease epidemic
• Ensure strategic planning and coordination of the fight against Alzheimer’s across the federal government as a whole
• Establish an inter-agency council to work with the Secretary of Health and Human Services to give a full assessment of what needs to be done to address the threat of Alzheimer’s on multiple fronts including care, research and support
• Build on the recommendations of the Alzheimer’s Study Group, an independent, bipartisan panel created to evaluate the government’s current efforts to combat the disease and the work of the Alzheimer’s Association
We’ve Started to Have Success!

Public Law 111–375
111th Congress

An Act
To establish the National Alzheimer’s Project.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,
SECTION 1. SHORT TITLE.
This Act may be cited as the “National Alzheimer’s Project Act”.

SEC. 2. THE NATIONAL ALZHEIMER’S PROJECT.
(a) DEFINITION OF ALZHEIMER’S.—In this Act, the term “Alzheimer’s” means Alzheimer’s disease and related dementias.
(b) ESTABLISHMENT.—There is established in the Office of the Secretary of Health and Human Services the National Alzheimer’s Project (referred to in this Act as the “Project”).
(c) PURPOSE OF THE PROJECT.—The Secretary of Health and Human Services, the Secretary’s designee shall...
National Alzheimer’s Project Act

• 50,000 emails sent to congressional offices

• Over 1,000 advocate meetings with members of Congress and White House

• 3,000 emails to the secretary Health and Human Services

• 50 researchers in cross-country Breakthrough Ride
  – 112,000 petition signatures delivered to Congress and the White House

• Need for national plan integrated into every media opportunity
From ACT to ACTION

• Over 130 public inputs sessions held around the country
• Tele-Town Hall
  – Over 43,000 Americans participated
  – Online comments
• Issued *Frontlines Report* on what public wants to see in national plan
• Made recommendations for membership of Advisory Council
250,000 Americans signed the petition

To the President of the United States

A PETITION FOR A STRONG NATIONAL ALZHEIMER'S PLAN

Families Facing Alzheimer's Disease Can't Wait

We, the undersigned, call on the President to issue a strong National Alzheimer's Plan to help the millions of Americans now affected by Alzheimer's disease, and the many millions more at risk.

Alzheimer's won't wait.

Today, more than 5 million Americans are facing the challenges of Alzheimer's. This number could rise to 16 million by 2050 if we do not act.

Right now, nearly 15 million Americans serve as caregivers, and this is projected to soar to 45 million in that same timeframe.

The cost of inaction is too high. Alzheimer's will cost the nation $200 billion this year. This will rise to $1 trillion by 2050, bankrupting families and our health care system.

Alzheimer's is the sixth-leading cause of death in the United States.

SIGN THE PETITION

236,118 signatures so far!

Alzheimer's can't wait. We need a federal commitment in order to change the course of Alzheimer's disease. Tell President Obama millions of families are counting on him to fulfill the potential of the National Alzheimer's Project Act.

First name: 

Last name: 

Email: 

Address 1: 

Address 2: 

City: 

State: 

ZIP: 

Privacy Policy

SIGN NOW

By signing, you accept alz.org's terms of service and may receive updates on this and related matters.
10 Challenges from the *Frontlines Report*

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

Five Goals

1. Prevent and Effectively Treat Alzheimer’s Disease by 2025
2. Enhance Care Quality and Efficiency
3. Expand Supports for People with Alzheimer’s Disease and Their Families
4. Enhance Public Awareness and Engagement
5. Improve Data to Track Progress
$100 Million Request for Fiscal Year 2013

Research: $80
Caregivers: $10.5
Awareness: $4.2
Provider Ed: $4
Data: $1.3
$100 on research vs. $28,000 on care
A Commitment to Research Works!

2011 NIH Research Funding
In Billions of Dollars

- Cancer: $5.8
- Heart Disease: $4.3
- HIV: $3.1
- Alzheimer's Disease: $0.450
Key State Issues

• **State Plans in all 50 states** (39 state plans/in development)
  - Creates infrastructure and accountability
  - Comprehensive state strategy to address needs of people living with Alzheimer’s

• **Uniform Adult Guardianship Jurisdiction** (32 states)
  - Establishes framework allowing state court judges in different states to communicate with each other about adult guardianship
  - Establishes uniform set of rules for determining jurisdiction
Meeting the needs of Individuals with Younger-Onset Alzheimer’s: Early-Stage Programs and Services
What We Know

Experiences of early-stage individuals may include:

- Reluctant to admit their condition to others
- Perception of feeling abandoned, being alone even when they are not
- Overpowering feeling of isolation
- Desire to seek connections and support
What Are Early-Stage Individuals Saying?

• Remain active and vital as long as possible
• Want services beyond traditional supportive programs
• Make meaningful contributions
• Activities that bring purpose to their life
• Remain the people they are
• Connect with others having a similar experience
Early-Stage Programs and Services

- Education Programs
- Early-Stage Support Groups
- Early-Stage Social Engagement Program (Pilot)
- AlzConnected™
- Alzheimer’s Navigator™
- Community Resource Finder
- TrialMatch®
- National Early-Stage Advisory Group
- Driving and Dementia Resource Center
- “I have Alzheimer’s” on alz.org
Early-Stage Programs

Education Programs

• Know the 10 Signs
• The Basics of Alzheimer’s Disease
• Living with Alzheimer’s: For People with Alzheimer’s
• Living With Alzheimer’s for Younger-Onset Alzheimer’s
• Legal and Financial Planning
• Driving and Dementia Resource Center

Support Groups

• Provide safe and mutually-supportive environment of peers
• Offer
  – dementia-related education
  – emotional support
  – connections with resources
• Allows participants to share with others who understand because they are going through similar experiences
Anyone can listen.
Not everyone can understand.

A diagnosis of Alzheimer’s or a related dementia can leave a person unsure of where to turn and who to talk to. The Alzheimer’s Association Early-Stage Peer-to-Peer Outreach Program is a unique service designed to connect newly diagnosed individuals with others living in the early stage of the disease. Via telephone, volunteers will answer questions, share their perspectives and experiences, and provide information about Alzheimer’s Association programs and services.

Contact your local chapter to learn more.
800.272.3900
alz.org

Life takes turns.
It helps to have friends around every corner.

A diagnosis of Alzheimer’s or a related dementia is likely not the life path one envisions. One way to face this disease is to continue to enjoy life. The Alzheimer’s Association Early-Stage Social Engagement Program offers a fun and comfortable way for people in the early stage of the disease to get out, get active and get connected with like individuals through a variety of community-based activities and social events.

Contact your local chapter to learn more and to sign up.
800.272.3900
alz.org
www.alzconnected.org
The stigma of Alzheimer's Disease

**RussB**

Posted: Friday, July 13, 2012 6:43 AM

Joined: 1/23/2012
Posts: 15

Do you share your diagnosis openly with others or do you fear the stigma of Alzheimer's (and other types of dementia)? I will start - I am open about my Alzheimer's disease and even speak to many groups about living with Alzheimer's.

**nomemo**

Posted: Friday, July 13, 2012 10:47 AM

Joined: 3/21/2012
Posts: 118

I have shared with my closest friends, former co-workers, and immediate family members. Once I had my diagnosis of frontotemporal dementia, I felt the need to explain my outrageous behaviors and personality changes because I am sure (especially co-workers) they were wondering, “What in the world has happened to her?” My co-workers and other friends rallied around me at first...now, not so much. That’s not to say they don’t care; but I think that now the “newness” of knowing has worn off, life goes on. As it should, I guess. My family, well, I may as well have told them I had the cold or flu, but I didn’t expect much support from them anymore, so I was not surprised. I have tried to educate as much as I can, but I find that I’m educating myself most of the time. Which, for me, is a good thing.

russb, how have people responded to you? Friends, family members?
Alzheimer’s Navigator

Alzheimer’s disease creates questions. We can guide you to answers. What is Alzheimer’s Navigator? get started

Map out a plan to approach Alzheimer’s
When facing Alzheimer’s disease, there are a lot of things to consider. We can help you figure out your next steps. Complete a series of short surveys to receive a customized Action Plan designed just for you, that will include:

- Step-by-step guidance
- Alzheimer’s disease information you can trust
- Programs and services in your community

Sample questions from the short surveys
1. Do you find that you have stopped or limited doing things you used to enjoy?
2. Have you thought about the type of care you will need and how you will pay for it?
3. Does the person with dementia tend to become more confused and agitated in the late afternoon or evening?
Welcome Survey

Page 1 of 1

1. Do you have a basic understanding of Alzheimer’s disease or related dementias?
   a. ☐ No, I do not know very much about Alzheimer’s disease or related dementias.
   b. ☐ I know a little bit about it, but want to learn more.
   c. ☐ Yes, I know quite a bit about Alzheimer’s disease or related dementias.

2. Are you prepared for the changes that will occur in your life as a result of your diagnosis?
   a. ☐ Yes, I am aware of the changes that will occur and am prepared.
   b. ☐ I know a little about the changes that will occur but would like to learn more about how to prepare.
   c. ☐ I do not know very much about the changes that will occur and am not prepared for how these changes will affect my life.

3. Do you feel comfortable talking with your doctor about Alzheimer’s or dementia and what to expect as the disease progresses?
   a. ☐ No. I do not feel comfortable talking with or working with the doctor. I often leave the appointment with unanswered questions.
   b. ☐ I like the doctor and usually get my questions answered, but sometimes I find I have forgotten to ask some questions or mention some symptoms.
   c. ☐ Yes. I work well with the doctor and he/she is an important part of my care team.

4. Are you independent in doing day to day activities such as paying bills, shopping, or household tasks?
   a. ☐ No. I need a little assistance with some day to day activities but can still handle some activities independently (for example: I can create a shopping list but need someone to do the grocery shopping.
   b. ☐ Yes, I am independent but have noticed I am having more difficulty with some day to day activities.
   c. ☐ Yes. I am independent and don’t need any help at this time.
Welcome M

The Alzheimer’s Navigator is designed so you can move at your own pace - take one survey a day or week!

Surveys
By answering additional surveys (below left), you will receive customized action steps. Surveys may be taken in one sitting, or saved and finished at your convenience. When your situation changes, you can re-take surveys to update your plan.

Your Action Plan
This plan is offered as the result of your survey responses. Each action step links you to information and resources.

You can also call the Alzheimer’s Association 24/7 Helpline at 1.800.272.3900 to speak with a care consultant.

Surveys
2 of 9 recommended surveys complete (submitted)

Recommended Surveys
Driving
Submitted on 7/9/2012 at 10:02 AM

Knowledge of Alzheimer’s
0% questions answered (not yet submitted)

Action Plan

Priority

3 of 30 action steps complete

Priority Steps

Learn about Alzheimer’s Association Comfort Zone®

Alzheimer’s Association Comfort Zone® is a Web-based application that works with GPS and cellular technology to manage the location of a person with dementia.

Learn about local transportation resources in your community.

There are many transportation options that people with Alzheimer’s can explore in order to travel independently and remain in control of their mobility. Use the Community Resource Finder (alz.org/communityresourcefinder) to learn more about the available options in your area.

www.alzheimersnavigator.org
Community Resource Finder

Find Resources in 2 Easy Steps:

1. Enter the location of where you need services.
   ZIP Code: ________  -or-  City: ________  State: Select State

2. Select the category (definitions) you want to see search results for. Then view the search results and narrow down your choices.

- Residential Care
  - Adult Family Homes
  - Assisted Living Communities
  - Independent Living Facilities
  - Residential Facilities
  - Skilled Nursing Facilities

- Medical Care
  - Diabetes Education Centers
  - Hospice
  - Hospitals
  - Hyperbaric Treatment Centers
  - Medical Equipment Suppliers

- Alzheimer's Association
  - Education Programs
  - Support Groups
  - Early Stage Programs Events

- Services
  - Aging and Disability Resource Centers
  - Adult Day Programs
  - Area Agencies on Aging
  - Elder Law Attorneys
  - Geriatric Care Managers
  - Home Care

www.communityresourcefinder.org
<table>
<thead>
<tr>
<th>Data From</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>June 2010- June 2012</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web Visits</td>
<td>110,785</td>
</tr>
<tr>
<td>New Calls</td>
<td>10,921</td>
</tr>
<tr>
<td>New Profiles Started</td>
<td>33,162</td>
</tr>
<tr>
<td>New Profiles Completed</td>
<td>27,077</td>
</tr>
<tr>
<td>Referrals to Matched Sites</td>
<td>6,785</td>
</tr>
<tr>
<td>Returning Users Updating a Profile</td>
<td>16,557</td>
</tr>
<tr>
<td>Follow-up Calls</td>
<td>18,650</td>
</tr>
</tbody>
</table>
Alzheimer’s Association National Early-Stage Advisory Group

Role of a National Early-Stage Advisor

• raise awareness about early-stage issues
• inform the public about the work of the Association
• act as a spokespersons for national media opportunities
• advocate to increase funding for support programs and research
• provide input to external groups (on behalf of the Association) regarding early-stage issues
• support the Association in providing the most appropriate services for people living with early-stage
Dementia & Driving Resource Center

Driving demands quick reaction time and fast decision making — because of this, a person with Alzheimer’s will eventually become unable to drive. Dealing with the issue early on can help ease the transition.

Watch how four families deal with different issues related to dementia and driving.

A Supportive Conversation: Frank has early stage Alzheimer’s and the doctor said it’s no longer safe for him to drive. His wife doesn’t drive, but knows it’s time to discuss finding alternative transportation. Full Screen

Having the conversation
I Have Alzheimer's Disease

Early-Stage Initiatives Overview

What You Need to Know
- Get Educated
- Know What To Expect
- Plan For the Future
- Find Peer Support and Stay Engaged
- Stigma of the Disease

Live Your Best Life
- Live Well
- Raise Your Voice
- Find Support
- Daily Coping Strategies
- Intimacy and Relationships

EMPOWERMENT
Over 80 Chapters Nationwide
300 Points of Service
Questions?