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

Olive Branch, Mississippi August 15, 2012

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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"



2012 ALZHEIMER'S DISEASE FACTS AND FIGURES

Includes a Special Report on People with Alzheimer's Disease and Other Dementias Who Live Alone

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

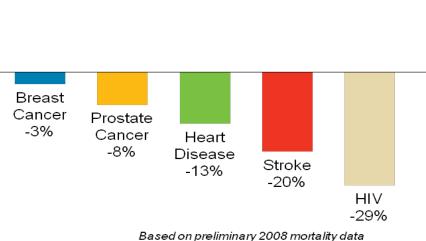
- Increased risk of
 - Missed or delayed diagnosis
 - Nursing home placement
 - Falls
 - Self neglect

- 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



Based on premimary 2000 monancy dat

Change in the Number of Deaths Between 2000 and 2008

Alzheimer's Disease 66%

The Alzheimer's Caregiver

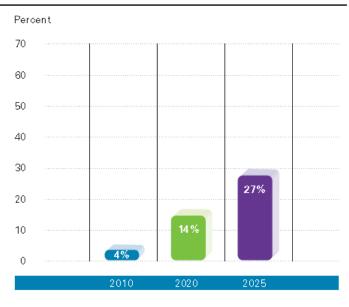
- Nearly 15 million people provide unpaid care for Alzheimer's or other dementias
 - 77% of caregivers were between the ages of 35 64 years
 - 60% are women
- Eighty percent of care provided at home is delivered by family caregivers
 - 44 percent are employed full or part time
 - 65 percent said they 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 Year 65 - 7475-84 85+ Total % change from 2000 2000 3,400 26,000 22,000 51,000 2010 3,200 26,000 24,000 53,000 4% 2020 4,100 28,000 26,000 58,000 14% 65,000 2025 4,700 33,000 27,000 27%



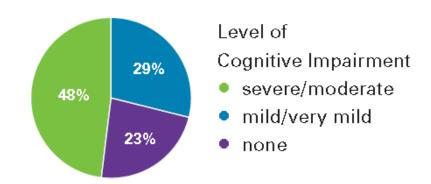
Percentage Change in Number with Alzheimer's Disease Compared to 2000



Cognitive Impairment in Nursing Home Residents, 2009

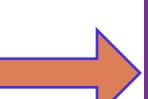
Total Nursing Home Residents

29,306



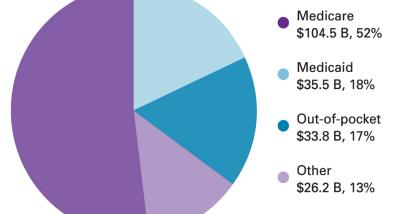
Cost to Nation

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.



Aggregate Costs of Care by Payer for Americans Age 65 and Older with Alzheimer's Disease and Other Dementias, 2012*





*Data are in 2012 dollars.

Source: Alzheimer's Association 2012 Alzheimer's Disease Facts and Figures.

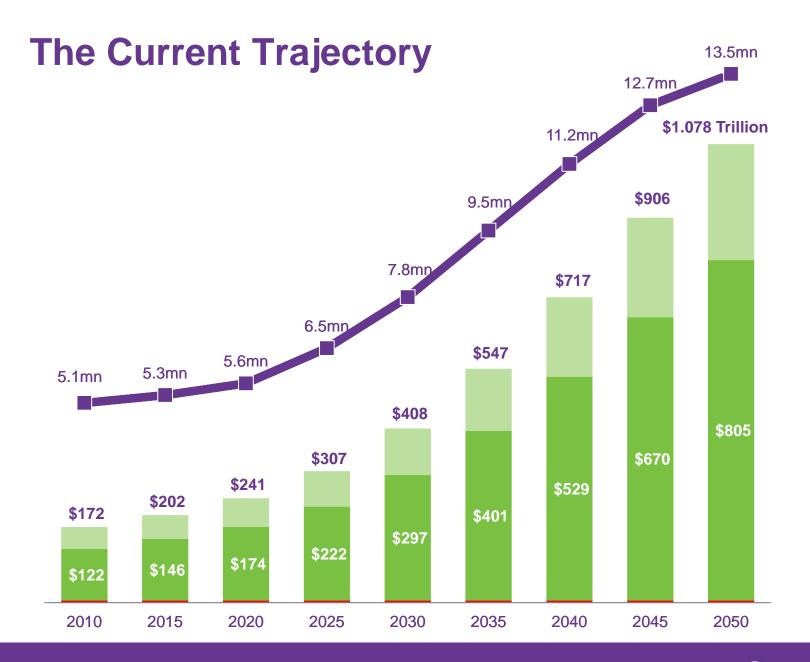


Why is Alzheimer's such a cost driver?



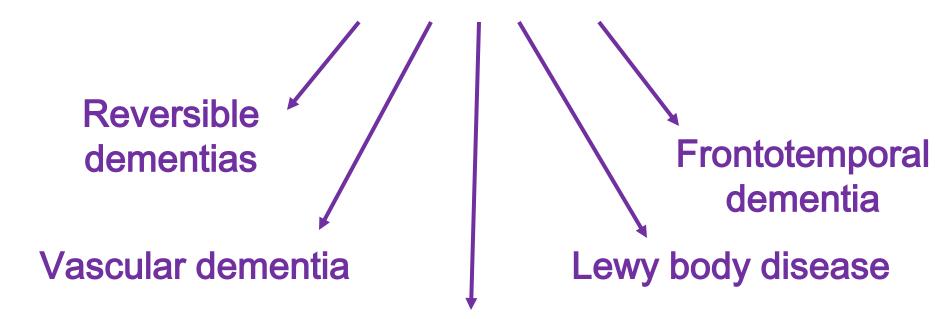
Most people with Alzheimer's have 1 or more other serious chronic conditions, and dementia complicates the management of other conditions.

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.



Understanding Dementia

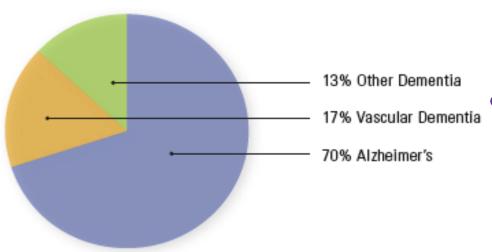
Dementia



Alzheimer's disease

Irreversible Types of Dementia

Causes of Dementia in People Aged 71+, ADAMS, 2002



 Alzheimer's disease: the most common type of dementia

Up to 80% of people with dementia have
 Alzheimer's disease

Created from data from Plassman et al. 2

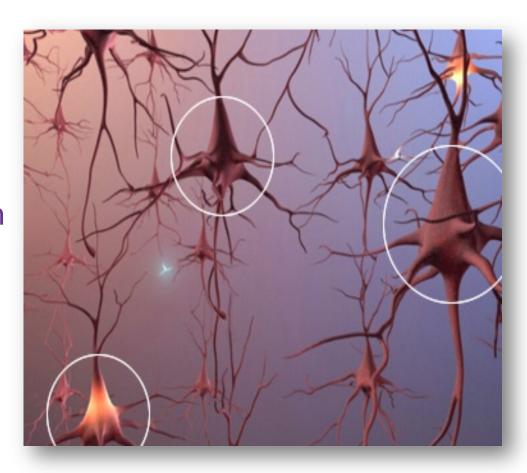
What is Alzheimer's disease?

Alzheimer's disease

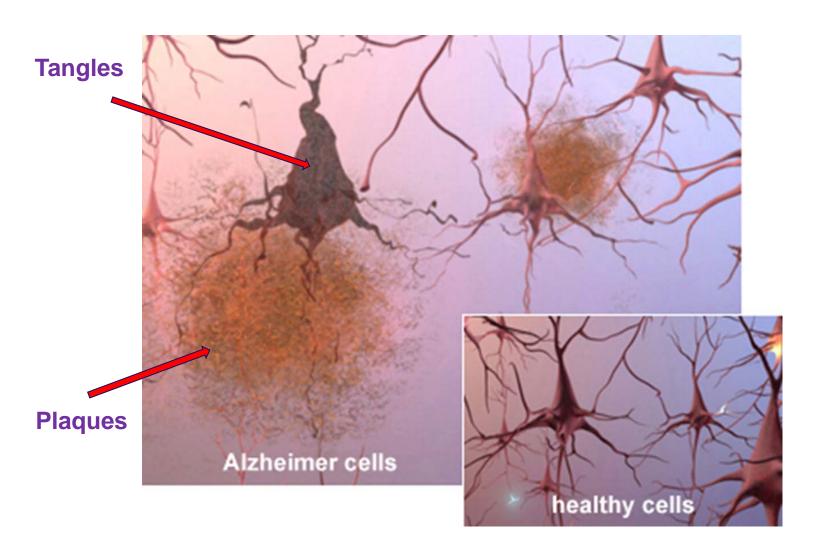
- Is a brain disorder
- Is a progressive disease
- Is the most common form of dementia
- Is fatal

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



Major Risk Factors

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

Estimated Percentage of Americans Aged 71+ with Dementia by Gender, ADAMS, 2002



Created from data from Plassman et al.2

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 Changes

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

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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

Jan. 4, 2011 [S. 3036]

Alzheimer's Project Act. 42 USC 11201

42 USC 11225.

National

note.

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

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 43,000Americans participated
 - Online comments

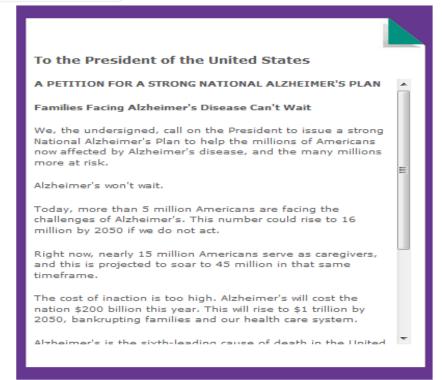
- Issued Frontlines
 Report on what public
 wants to see in
 national plan
- Made recommendations for membership of Advisory Council

250,000 Americans signed the petition



alz.org | petition

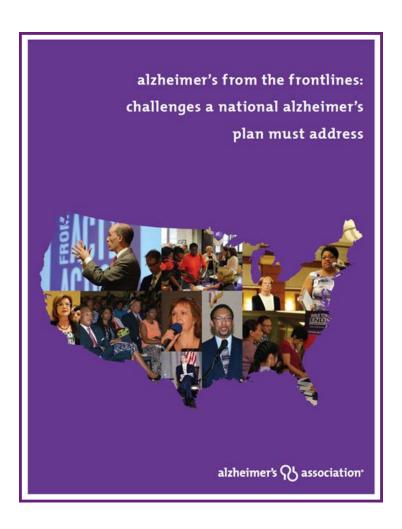
alzheimer's Pb association



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

10 Challenges from the Frontlines Report



- Specific challenges facing diverse communities
- Specific challenges facing those with younger-onset Alzheimer's
- Unprepared caregivers
- III-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







Research: \$80 Caregivers: \$10.5

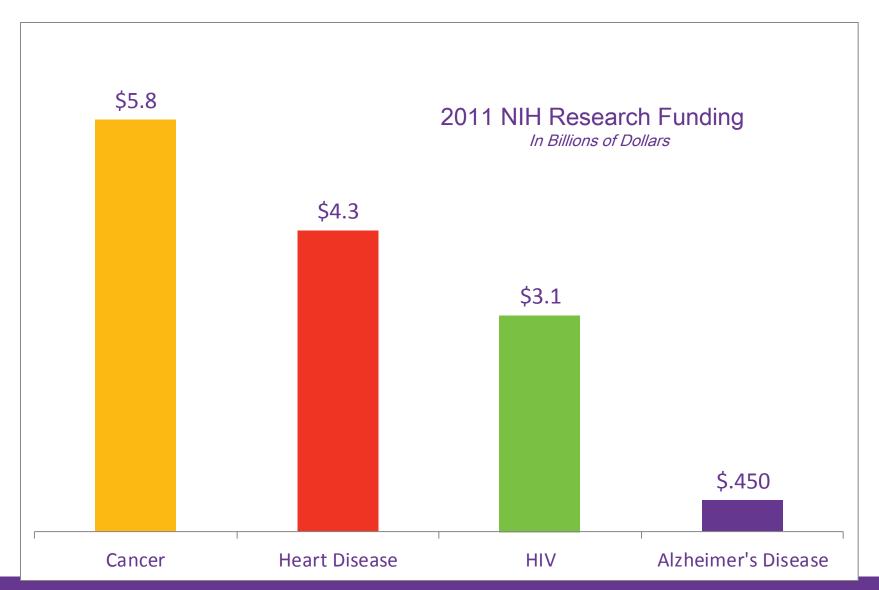
Awareness: \$4.2 Provider Ed: \$4

Data:

\$100 on research vs. \$28,000 on care

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A Commitment to Research Works!



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

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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)
- AlzConnectedTM
- 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

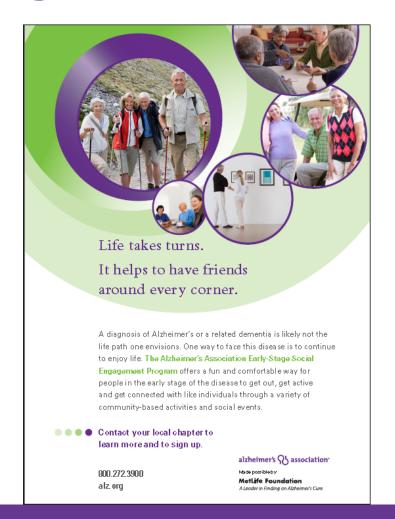
- Know the 10 Signs
- The Basics of Alzheimer's Disease
- Living with Alzheimer's: For People with Alzheimer's
- Living With Alzheimer's for Younger-Onset Alzheimer's
- Legal and Financial Planning
- Driving and Dementia
 Resource Center

Support Groups

- Provide safe and mutuallysupportive 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

Early-Stage Social Engagement Pilot Program







www.alzconnected.org

you

message boards

az connected™

solutions

inbox 🕕

connections 2

groups

photos

AIAIA

Archive Discussion Board » Younger-Onset AD or Other Dementia » The stigma of Alzheimers Disease



The stigma of Alzheimers 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 Alzheimers (and other types of dementia) I will start - I am open about my Alzheimers disease and even speak to many groups about living with Alzheimers.



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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 workers. 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 happend to her?" my co-workers and other friends rallied around me at first...now, not so much. that's not to say that 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 really didn't expect much support from them anyhow, 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?

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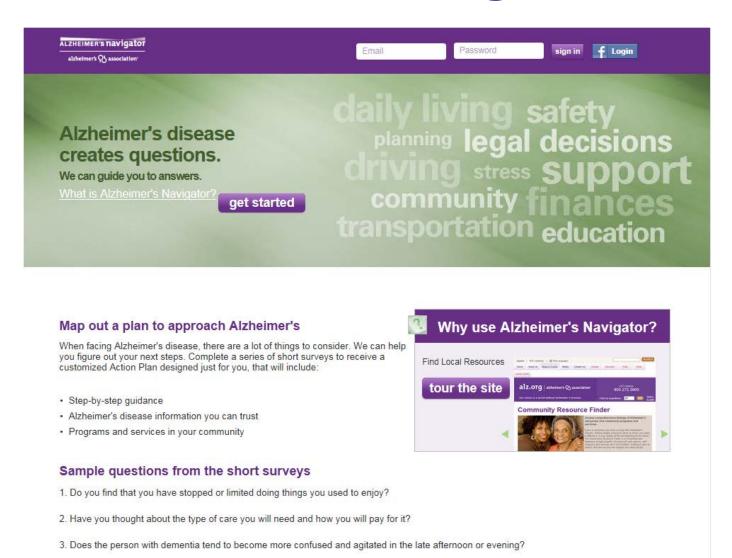


113Total Posts



Joined ITIS L. 2/23/09 109Total Posts

Alzheimer's Navigator



a. \square 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

c. \(\subseteq \text{Yes. I work well with the doctor and he/she is an important part of my care team.} \)

shopping list but need someone to do the grocery shopping.

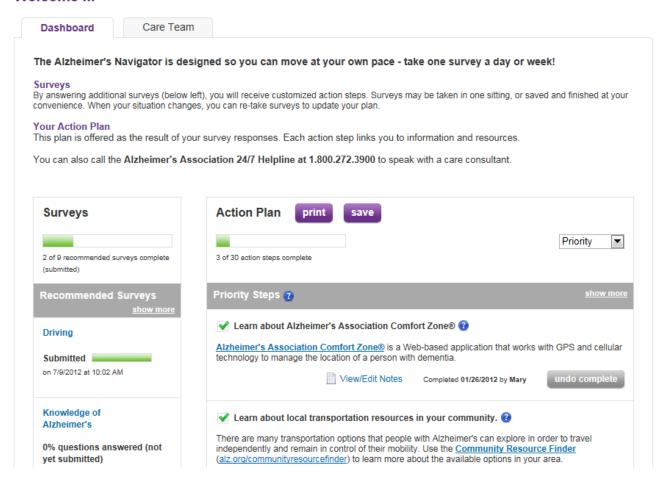
c.

Yes. I am independent and don't need any help at this time.

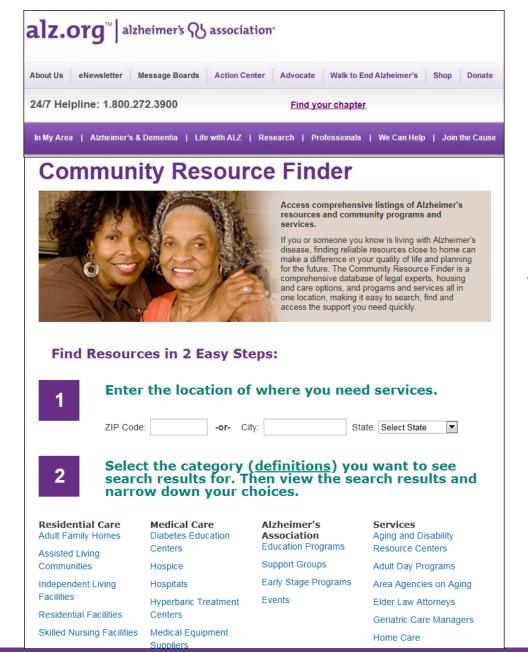
4. Are you independent in doing day to day activities such as paying bills, shopping, or household tasks?

b. Tyes, I am independent but have noticed I am having more difficulty with some day to day activities.

Welcome M



www.alzheimersnavigator.org



www.communityresourcefinder.org

alzheimer's % association trialmatch

Web Visits	110,785
New Calls	10,921
New Profiles Started	33,162
New Profiles Completed	27,077
Referrals to Matched Sites	6,785
Returning Users Updating a Profile	16,557
Follow-up Calls	18,650

Data From June 2010- June 2012

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





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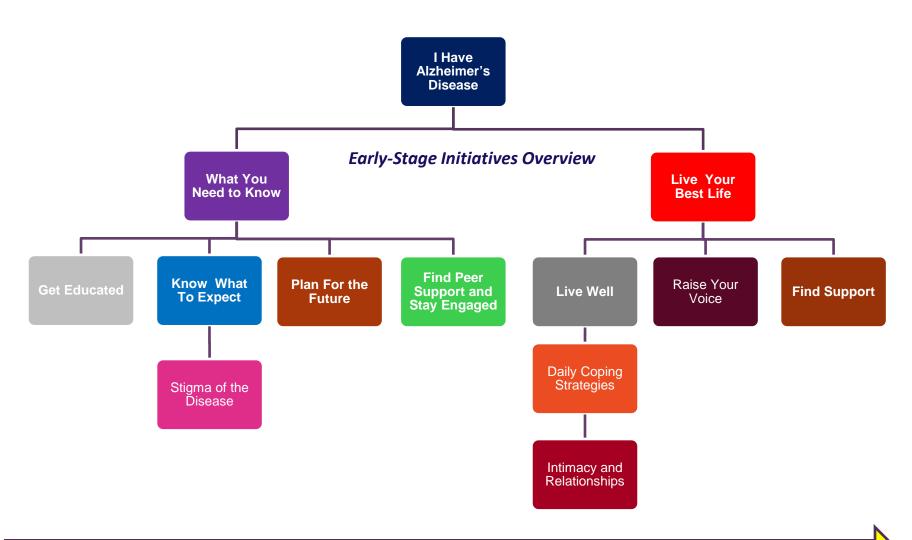
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Tweet 7

Having the conversation

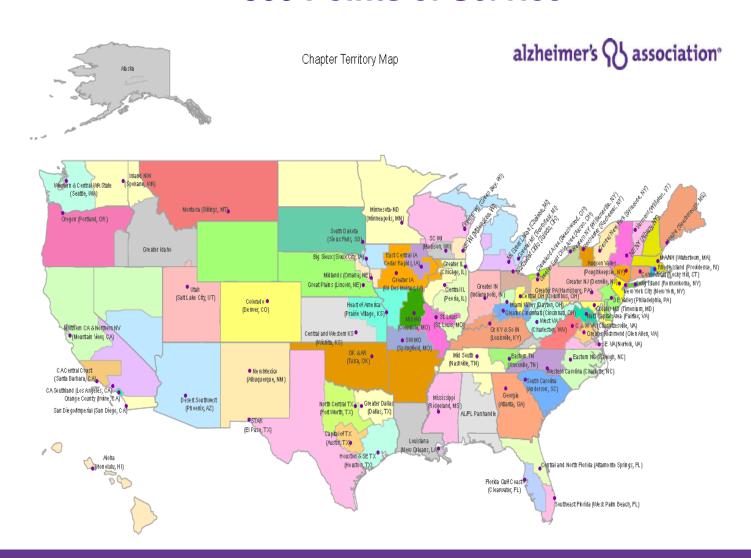
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EMPOWERMENT

Over 80 Chapters Nationwide 300 Points of Service



Questions?