

**Nevada State Plan for Alzheimer's disease
Work Group
Impact of the Disease, and
Safety & Independence**

Liaison: Ruth Gay

Director, Public Policy and Advocacy
Alzheimer's Association

Kimberly Weber
Policy Specialist
Alzheimer's Association

Participants:

Sally Crawford Ramm, JD
State of Nevada, Aging and Disability Services

Julie Lasko, RN, MSN

Angie Pratt

Director of Northern Nevada
Alzheimer's Association

Judge Egan Walker
Washoe Courts

Diane Ross, CEO
The Continuum

Christine Terry
Program Manager, Desert Southwest Chapter
Alzheimer's Association

Kat Hartley
Caregiver

Impact of the Disease

- Current and projected impact of Alzheimer's disease to Nevada
- Overall impact of younger onset v. older onset Alzheimer's
- Cost of care to Nevada (public and private entities)
- **Cost/Availability/Capacity** of: in home care agencies, private memory care facilities, group homes, skilled nursing facilities, hospice, family caregivers, adult day health centers, home health, long-term care facilities, etc. (the regulatory issues on these facilities is being considered by the Quality of Care and Regulation Workgroup, but our task will be on Access and Impact of this topic)
- Participation in clinical trials
- Hospitalization, Emergency Room
- Collaboration opportunities to enhance existing research efforts
- Cost - Medicare, Medicaid, Veterans Assistance, private insurance

Safety and Independence Factors

- Community education
 - Including Emergency Room staff, first responders and Hospital staff
- Guardianship Regulation and oversight of Guardians
- Out of State Placement
- Legal resources
- Prevention of abuse and exploitation -
- Wandering and general safety issues
- Emergency preparedness
- Gaps in service
- Cultural issues and considerations

**EXHIBIT JJ – Alzheimer's
Document consists of 33 pages.
Entire document provided.
Meeting Date 08-22-12**

Alzheimer's State Plan Task Force

Work group – Impact on the State, Safety and Independence

Meeting notes, August 1, 2012

Next Meeting Dates: August 9th 10:00 a.m. – 12:00 p.m.
August 20 – 9:00 a.m. – 11:00 a.m.

Assignments:

Egan Walker: Research and Data on morbidity and mortality on moving people away from families or community.

Sally Ramm: What might Surrogate Consent look like? Are there examples of how we could make it workable in Nevada?

Angie Pratt: Early Onset problems and issues, and numbers

Diane Ross: Affordable Care Exchange – does this apply to people with Alzheimer's, or is this applicable to younger onset individuals and their families?

Ruth Gay: CMS Innovation Grants or Waivers
Recent Data on Alzheimer's disease (Generation Alzheimer's)
ER Friendly Hospitals

Summary: Topics that rose to the top for discussion:

Out of State Placement – solutions are difficult and it's a good deal about the cost to the state. Discussion that solutions are expensive and may not be easily changeable. Sally suggested that this topic might be one that could overwhelm our discussions and not leave us time to get to any of the others. Concerns: We are funding other States' infrastructures while ours in Nevada is falling apart, and ultimately it costs more money in other lives and care than is recognized.

**Guardianship Oversight – who checks on people when they are placed out of state, and especially how can we assure their safety or well being, or even if the capacity of the place they are in has the ability any better than in Nevada to care for them.

*Judge Egan Walker to do some research on morbidity and mortality with moving individuals away from important links/family/connections

Earlier Detection and Diagnosis is very important. Allowing people to plan, giving people choices, and allowing individuals the ability to know what they are living with is critical, not to

mention the need to know it, but there seems to be no incentive to do either early screening. Julie noted that the AHRZ provides Health Recommendations on many diseases as to whether to work it up or treat. There is absolutely no information nor recommendations to either work it up or treat – considered a disease where there is no pay off to provide detection and treatment for.

Research – What is available in terms of Medical research for families – Clinical trials, medications and other options? Are persons with Dementia and Alzheimer's able legally in Nevada to give appropriate consent? Is a Surrogate Consent possible for research purposes?

**Sally Ramm to do some Research on access for families and Surrogate consent

**Need for Education and Training– This seems to be an overriding issue. Supervisors in the work place don't understand the disease, or the problems caregivers encounter. One reason people are placed out of state is because people don't know how to recognize the symptoms, don't work them up or don't know how to manage the disease.

Julie noted that there are some new Emergency Room Training Programs on Caring for Seniors and there is NOTHING about Dementia in the training – although this will affect anywhere from 20 – 50% of that population depending on their age.

The need to prepare for the coming demand for services is critical, and if we don't do it now, the costs in the future will be even worse

Primary Care Docs need education and recognizing when to refer to a Neurologist.

**Ruth to get some data on AD to give context to this discussion.

Crisis care in Hospital/ Emergency room situations are extreme. Sometimes families in desperation abandon their loved in the ER because they don't know how else to get care and help. Many are uninsured and cannot pay for medical care or other services. Emergency Rooms do not want to take people with Dementia and will try not to admit them or provide services to them. It's a double edged sword.

- Possible use of Urgent Care Centers may be an option REMSA – Ambulance system in the Northern Nevada area is getting special training for the staff so they can take people to urgent care centers instead of the ER. However – ER cannot require up front payment for services and the Urgent care centers can. Is there a way to use the Low Cost Clinics in communities to provide some type of care/information/access to services.

**Ruth to provide some data on improving Hospital Care for this population

Younger Onset – Adds another dimension and is a big problem for families, especially when children are involved. The family may lose the primary job, health insurance and perhaps even their home if their income is impacted in these ways. Remaining spouse must make decisions

about quitting their job or paying for care. There have been cases where children had to quit school to stay home and help with care or help with income.

**Diane Ross to do some research on the Affordable Care Exchange and whether people with dementia are included

** Angie to bring information on numbers and impact of those with Younger Onset

**Financing/ Cost of Care – Families can't afford the care that is needed, or they are forced to go into Medicaid to get care when before they were covered in other ways. It impoverishes families sometimes immediately when placement occurs, sometimes over a few years of providing extensive and expensive care. This can be in direct personal costs and in an Adult Child or other Caregiver having to reduce hours at work or leave a job to provide the needed care. There are many Tangible and non tangible costs with the Disease, one program that might be replicated is the Mental Health outreach. – this allows people to receive assessment and services in their community. We would have to have a medical outreach type program, but could be helpful in rural communities

- Respite Care can be a big help – even as a short term way to both save costs for the family and give Caregivers a break

**Ruth to do some research on Centers for medicare and Medicaid innovation grants and waivers for funding

NOT DISCUSSED:

Safety, Wandering, abuse prevention, other safety issues
Emergency preparedness

Alzheimer's State Plan Task Force

Work group – Impact on the State, Safety and Independence

Agenda: August 9, 2012

10:00 – Welcome and introductions

Ruth Gay, Kimberly Weber, Angie Pratt, Sally Crawford Ramm, Julie Lasko, and Kat Hartley were in attendance.

10:10 - Brief overview of previous discussion. Topics not discussed:

Safety, Wandering, abuse prevention, other safety issues, Emergency preparedness

10:15 – Announcement –Town Hall, September 13, 2012, Northern Nevada.

Town Hall, August 28, Las Vegas- details to follow

10:20 - - 10:50 Guardianship Oversight

What are the gaps?

- *The courts in most of the States do not follow up on whether the annual reports are being followed up on. This has become a voluntary reporting. We often find mis-management of funds, placement in facilities that are not appropriate. This tends to happen with family guardians, not so much public or private guardians. Sometimes are inappropriately kept at home in a non safe situation. The only legal oversight is the court. The law is pretty lenient for family member guardians – must be willing and/an absence of a felony.*

Are there Recommendations for this Category?

Courts should be required and funded to monitor the Guardians and enforce and review the annual reporting requirements. Do we need to specify that we are talking about guardians of Adults.

The State should consider a “Friends of the Court” program that would train volunteers who could follow up and check on individuals under guardianship in the community.

10:50 – 11:20 Need for Education and Training

Are there Priority communities that need some level of training? How do we determine how best to describe and identify who these are?

- *First responders, Sheriff and Police, Fire Department should have a specified number of hours of training in recognition and how to handle/respond to people with Dementia and*

Alzheimer's. ER Personnel should have special training for care for people who are identified with dementia/Alzheimer's. Many people with dementia are living alone. Emergency room personnel needs to know how to recognize and manage care for people with dementia.

- Nursing school should have it in their curriculum. There is a gap in basic nursing education and for staff nurses. Needs to be highlighted more for those who are in leadership positions.*
- Once someone is admitted to a Hospital – are they appropriately assessed as to whether dementia is present, can we address pain and other behavioral issues through more appropriate assessment so that people with dementia – whether it's in their chart or not*
- Inappropriate discharge planning from hospitals that result in repeat visits, because the care at home is not adequate or safe, and family cannot manage. Having some sort of Care Coordination/Care Management for people as they are discharged to ensure a more successful discharge process.*

What would a broad recommendation (s) look like for this category?

- Consider developing a Crisis Intervention team that includes specialized training for people, so Social Worker may travel with police when a call goes out. This model has made a big different in how people with Mental Health issues are handled. Could this technique be applied to people with Dementia? This could also apply to they way people manage in the Emergency Rooms as well.**
- Require hospitals, as a licensing requirement, to provide training for all new direct care staff at orientation and at annual intervals in assessing for, identification and management of people with dementia in hospital settings .**
- Consider “Coaching at discharge – Dr. Larry Weiss” for people with Dementia as they are discharged. Transition care programs, and consider the need for more Social Work involvement in discharge planning and case load**
- Consider Federal Waiver's currently becoming available that might fund innovative transition programs at the hospital level, that include Alzheimer's/Dementia as a special need population**

11:20 – 11:50 Financing/ Cost of Care –

What are the primary Gaps?

- *Lack of adequate care options for people besides SNF care on Medicaid. Families who don't have resources cannot access services until they are so far along that they need SNF care.*
- *Respite grants can help people, but sometimes people's income can be off by \$15.00 and therefore not be eligible*
- *Caregivers who have to quit their jobs to care for someone, and they themselves have to go on welfare or Medicaid because they lost their job and lost their health care in doing so.*

Are there Concrete Recommendations?

- **Adult Day programs and Respite funding can be a tremendous asset to families who are trying to work, are frail themselves or need a break, and are willing to keep their loved one at home. These programs should be sustained and funded securely to ensure they are able to continue these safety net services.**
- **Recognition should be given to the value of Adult Day Centers and Respite programs as Economically, Socially and Medically cost effective models and make the services available and affordable to more people. Consider a sliding fee scale for those above Medicaid eligibility levels to help sustain their funding, rather than Medicaid only.**
- **Engage the Alzheimer's Association and other private organizations to provide education to businesses through Alzheimer's Early Detection Alliance, to educate both about the disease and services for their employees in order to keep those valuable individuals employed in the workplace.**
- **Develop public service announcements to create awareness about the availability of services, programs in the community and to provide education about getting help for this disease.**
- **Develop partnerships with other organizations that also have co-morbidity with Alzheimer's disease to help get the word out about services and the added element of needed care, when dementia is present as well.**

Alzheimer's State Plan Task Force

Work group – Impact on the State, Safety and Independence

Notes: August 20, 2012

9:00 – 11:00 a.m.

Welcome and introductions

Present: Egan Walker, Sally Ramm, Diane Ross, Angie Pratt, Kimberly Weber, Kat Hartley, Christine Terry; Ruth Gay

Brief overview – Comments.

Included below are the key topics we are discussing this time and our notes or comments from our initial discussion on each.

Research

Gaps: Identifiable gaps in the Research area?

Maybe we need to wait for the research community to have some significant advances before we begin to weigh in on this type of legislation. Sally - There currently is no law that keeps people who are not under guardianship to participate in research, this is more of an ethical question. The need to protect individuals is the key difficulty especially when we can't guarantee that individuals won't have adverse side effects.

When someone is invited to participate in research, can make the decision and does so, but as the disease progresses, and they start to lose capacity to make that decision, then a power of attorney should be enacted.

Kat will connect with a person who is head of a notable Research Team and they do get consent in some way to do research with people with AD. Is informed consent part of the problem in enrollment? Are there other challenges with Research in the state that is related to consent, but to access, location or other problems?

Recommendations:

If we are not doing significant research in Nevada on Alzheimer's patients, it may be that we are misinterpreting current law as it applies to the Alzheimer's population. Education about the need for and ability of how to go about doing research safely and with appropriate precautions around consent may allow Nevada to contribute to this body of knowledge.

***Kat will gather some additional research from those at current research clinics to see if there and where there are barriers.

Crisis Care in Hospital/Emergency rooms

Gaps: What are the Gaps and Challenges in Hospital settings

- Should be some training of Dept heads, and sensitivity training because there are so many things that just don't work well for the people with dementia.
- People with dementia are more often hospitalized – just by data, and there are so many things that go on in transitions.
- Hospitals may no longer be reimbursed for certain procedures, and so there is a reluctance
- Is there a reluctance to treat in the hospital because the individual who has dementia may have a poor outcome, decline rapidly or become worse and it is a liability.
- Discharge planning gaps are big – staff are stretched, and person with dementia is discharged to an unsafe setting, that they are at risk for that.

Gaps: Emergency Room situations?

- Emergency room has some unique challenges for people who are already confused and disoriented in the ER setting
- People have delirium and other problems that make it difficult for the Hospital to respond to these folks in a way that allows them to handle the patient effectively.
- People dropped off who don't have someone with them, and need to be identified, connected to support and where to go after their stay – especially if homelessness or they are alone is identified.

Recommendations for Emergency room?

- Training/Education for Emergency room personnel and Ambulance services about dementia care and how to respond to people with dementia.

Recommendations for Hospital?

- Improved communication from hospital, they need to let family know what they can do: Need to have someone with the patient do they have someone who can sit with the loved one to spell family.
- Dementia specific training for Hospital Departments including Emergency personnel in options, management and treatment for people with dementia. For example benefits of training “St Lewis Hospital training” – to increase the detection and treatment to improve patient care, staff competency, preventing decline and safety for patient and staff.
- Investigate the federal funding through Medicare Innovations or CMS on opportunities to develop a transitions planning and/or avoid the hospital setting altogether ie: mobile dementia team approach.

Younger Onset Issues

Gaps: Can we identify some identifiable gaps?

- Senior Law project cannot serve people who are under 65 with younger onset dementia who could benefit from the services.
- Person with younger onset, State social workers were willing to be part of the process with the family, but they could not accompany the family to court, who would have benefitted from the social worker participating.
- No programs for people with younger onset, for instance people in their 40's and 50's don't fit well into a RCFE or Adult Day Care program that serves people in their 70's – 90's

Recommendations: Do we have specific recommendations for this specialized population of the whole?

- Remove age barriers that keep people with younger onset and other cognitive impairment from receiving services that seniors can receive (meals, legal services, respite). May be able to adopt language of the Older Americans Act at the Federal level.
- Explore “continuum of life” programs that do not discriminate between ages, but serve people based on need.
- State develop a “navigator” which might be a social worker, or other professional of some sort – who would help individuals who are in this situation to receive services, provide help for family, keep children in school, and other services.
- Explore innovative programs that would serve people with dementia specifically who are younger to better meet their needs.

Earlier Detection and diagnosis

Gaps: Where are there gaps in our ability or willingness to better identify/diagnose?

- Marketing around the need for and importance of early detection and identification, including when and why people should get diagnosed
- Businesses need training as to how to identify the problems, and who to help their staff who are informed
- MD's don't recognize or are reluctant to refer families, or don't see the need for diagnosis, and may indeed have Alzheimer's. May be easier to treat them without diagnosis, and are treated inappropriate, incorrectly, and delays diagnosis for family needs.

Recommendations: Can we make recommendations on this capability?

- Develop private/public partnerships to help educate the public about warning signs, and importance of seeking medical diagnosis for Alzheimer's in adults of all ages.
- Ongoing Training/Education for Primary Care doctors to recognize, identify and support diagnosis, and where to refer for services for individuals with early symptoms. Special emphasis on having the MD make referrals to people for services early in the disease process.

Next Meeting Date Scheduled: August 30 – 9:00 a.m. – 11:00 a.m.

- **Out of State Placement** is the key scheduled topic along with a final review of the previous recommendations. ** Sally Ramm will do a summary of previous work on this topic so that we can start with an understanding of that information.
- **Diane Ross to do some research on the Affordable Care Exchange and whether people with dementia are included

Young Onset Alzheimer's disease (AD) affects persons under the age of 65. At present, up to 5% of people with Alzheimer's have young onset which is linked to either rare genes that produce symptoms of AD in persons in their 30's, 40's, and 50's OR to a common type of AD young persons develop and not directly linked to genetics. This young onset diagnosis inordinately affects immediate family members and systems.

Areas relating to those diagnosed with young onset include, but are not limited to:

- Reactions to the diagnosis—Those with young onset and their family members may need counseling;
- The family—Spouse's/Partner's and extended family may feel a sense of loss or loneliness as a result of the diagnosis and therefore need counseling and support;
- Children—Children may experience a wide range of emotions and may feel that they did something to cause it or may become resentful that they have to take on more responsibilities. In addition, some children feel they must quit school and find a job to help support the family. Some children may feel they have to put their own futures on hold to help the immediate family during the journey of the disease. Therefore, the children of those with young onset may need special counseling and support.
- Job—A person with young onset AD may find work more difficult to perform as the AD progresses. Eventually they may need to reduce their work hours, change their job duties, or will not be able to work at all. This will affect not only the person's health insurance and benefits but possibly those of the whole family. Therefore, persons with young onset AD will need to find health care coverage for themselves and their family members.
- Debt—Reducing one's work hours, changing job duties and eventually not working at all may affect the ability to pay a mortgage, buy essentials, and continue to have a source of income. Therefore, persons with young onset AD and their care partners will need to meet with qualified financial consultants, find out about government assistance, and review personal disability insurance policies.
- Legal issues—a person with young onset AD will need to meet with an attorney to appoint a person to make financial and health care decision for their future.
- Future Care—the person with young onset AD and family members will need to make decisions about the day to day care of the person with dementia and the future care of the person with dementia. The family caregiver will need respite.

It is therefore recommended that those with young onset AD in Nevada be able to partake in all of the programs provided for persons with onset of AD after the age of 65 including but not limited to: respite resources, adult day resources, transportation resources, Medicaid enrollment, social security disability enrollment, prescription enrollments, etc. It is also recommended that the family be assigned a State social worker or navigator of services to help guide the family and meet the entire family's needs.

ALZHEIMER'S STATE PLAN TASK FORCE
Workgroup on Impact on the State, Independence and Safety
Report on Surrogate Consent
Sally Ramm, Aging & Disability Services
8/20/12

HISTORY

2007 – AB 578 – Submitted by the University of Nevada, Reno. Did not pass out of Assembly Committee on Health & Human Services.

2009 – AB 201 – Submitted by joint committee of Alzheimer's Association, University of Nevada, Reno, and other interested parties. Did not get assigned to Assembly Committee by Speaker.

STATUTE IN QUESTION

NRS 159.0805 Approval of court required before guardian may consent to certain treatment of or experiment on ward; conditions for approval.

1. Except as otherwise provided in subsection 2, a guardian shall not consent to:
 - (a) The experimental medical, biomedical or behavioral treatment of a ward;
 - (b) The sterilization of a ward; or
 - (c) The participation of a ward in any biomedical or behavioral experiment.
2. The guardian may consent to and commence any treatment or experiment described in subsection 1 if the guardian applies to and obtains from the court authority to consent to and commence the treatment or experiment.
3. The court may authorize the guardian to consent to and commence any treatment or experiment described in subsection 1 only if the treatment or experiment:
 - (a) Is of direct benefit to, and intended to preserve the life of or prevent serious impairment to the mental or physical health of, the ward; or
 - (b) Is intended to assist the ward to develop or regain the ward's abilities.(Added to NRS by 1981, 1933; A [1999, 1400](#); [2003, 1786](#); [2007, 2032](#))

ARGUMENTS

In favor of amending the law:

1. Law restricts research for Alzheimer's disease because it requires the surrogate decision-maker to spend the time and money to get the court's approval for participation of the ward in the research.
2. Law prevents people with cognitive deficits from participating in research because it requires that any treatment or experiment must be of direct benefit to the ward, and research cannot guarantee direct benefits.
3. As a result of the restrictive nature of the law, all research requiring surrogate decision making has been halted in Nevada.

In favor of not amending the law:

1. The suggested changes to the law remove too much protection of the ward's rights.
2. If court oversight is removed, then the remaining oversight is not strong enough or is non-existent, because there is no guarantee that all research is being conducted under the auspices of Institutional Review Boards.
3. If amended, the amendments must focus on adults with cognitive deficits to avoid affecting the protections for children and people with disabilities.
4. The argument that going to court to obtain permission to have the ward participate in medical research is not ward-centered. Instead, it speaks to the needs of the researchers and the surrogate decision-makers.

California law

It was argued that Nevada should reflect the California law. However, it was subsequently pointed out that the California law provided safeguards for the ward that were not included in what the University of Nevada, Reno proposed. For instance, California law contains a participant's bill of rights, a specific definition of informed consent, and requires a court order for consent by the surrogate. The research must pertain to the participant's conditions. (Note: This was from an e-mail in my file, and I haven't looked at the California law so I can't include cites.)

After AB 201 failed in 2009

Intent of the bill:

1. Allow participation in medical and behavioral research by adult persons with cognitive deficits (participants) who have surrogate decision-makers without the necessity of getting court approval.
2. The proposed legislation should specifically exclude medical experiments.
3. Insure that all research is conducted under and complies with the rules and regulations of an Institutional Review Board.
4. Protect the rights of the participants with a delineated "bill of rights."
5. List the persons who are allowed to act as surrogate decision-makers under this proposed legislation. Limit it to guardians and spouses. Parents of people over the age of 18 must become guardians anyway, so that would include them. This would eliminate younger children by eliminating the other possible decision-makers in the current bill.
6. Modify statute to allow for guardians to be surrogate decision-makers as described in this proposed legislation.

Discussion questions for AB 201:

1. Who and how could we have gotten others on board for this bill?
2. What were the major concerns legislators and others had with our proposal?
3. What were some strengths and weaknesses in the process we used to write our bill?
4. When our bill was rejected, how could we have responded? What could we have done that we didn't do?
5. What lessons have we learned? Do we wish to go forward again in the future?

Suggestions for recommendations to task force

Make changes in the statute as inconspicuous as possible, so advocates for other affected people will not be concerned about the effect of the changes on their constituencies. For instance, do not remove the requirement for a court order, as they are not that difficult to get, it does not affect that many people (only those with court-appointed guardians), and it provides necessary, additional oversight to protect those people who are not speaking for themselves.

Make certain any changes specifically address adults with cognitive deficits due to Alzheimer's or other dementia-type illnesses.

Propose a change to NRS 159.0805(3)(a) that does not require a direct benefit..., but instead says "Will not cause harm, pain or hardship to the adult ward."

Perhaps, instead of changing NRS 159.0805, a new statute should be proposed pertaining only to surrogate consent. Currently, the statute addresses "experiment" and "treatment" but does not specifically identify surrogate consent. If a definition of surrogate consent can be written to differentiate it from experimental, and the statute would pertain only to adults suffering from Alzheimer's or other types of dementia, then the requirements could be different without removing any of the necessary safeguards that are delineated in the current statute.

8/20/12

generation alzheimer's

the defining disease of the baby boomers



Introduction



This year, the first baby boomers turn 65 — when the risk of developing Alzheimer’s disease significantly increases. While Alzheimer’s is not normal aging, age is the greatest risk factor for the disease.

This means baby boomers are its next target.

With the first wave of baby boomers reaching age 65, there is an impending wave of new cases and new families that will have to face the devastating, deteriorating, debilitating and heartbreaking disease known as Alzheimer’s — a progressive and fatal brain disorder that causes problems with memory, thinking and behavior.

Eventually, Alzheimer’s kills, but not before it takes everything away from you. It steals a person’s memories, judgment and independence. It robs spouses of lifetime companions and children of parents and grandparents. It destroys the security

of families and depletes millions of dollars annually from family and government budgets.

It is expected an estimated 10 million baby boomers will develop Alzheimer’s. Of those who reach the age of 85, nearly one in two will get it. And because there is no way to prevent, cure or even slow the progression of the disease, every one of these 10 million baby boomers will either die with Alzheimer’s or from it.

Too many of America’s baby boomers will spend their retirement years either with Alzheimer’s or caring for someone who has it.

And it’s not just the person with Alzheimer’s who suffers — it’s also the caregivers. Caring for someone with Alzheimer’s disease negatively affects the caregiver’s health, employment, income and financial security. But that is nothing compared to the human cost — the toll it takes watching a loved one slowly disappear.

Unless we find a treatment or a cure, Alzheimer’s will become **the defining disease** of the Baby Boom Generation. They will be Generation Alzheimer’s.

Alzheimer's Is an Epidemic

Today, 5.3 million Americans have Alzheimer's disease. But it's only going to get worse — and fast.

Right now, we are unnecessarily losing the battle against Alzheimer's disease.

The first of the baby boomers are now turning 65. By 2030, the U.S. population aged 65 and over is expected to double, meaning there will be more and more Americans with Alzheimer's — as many as 16 million by mid-century, when there will be nearly 1 million new cases every year.

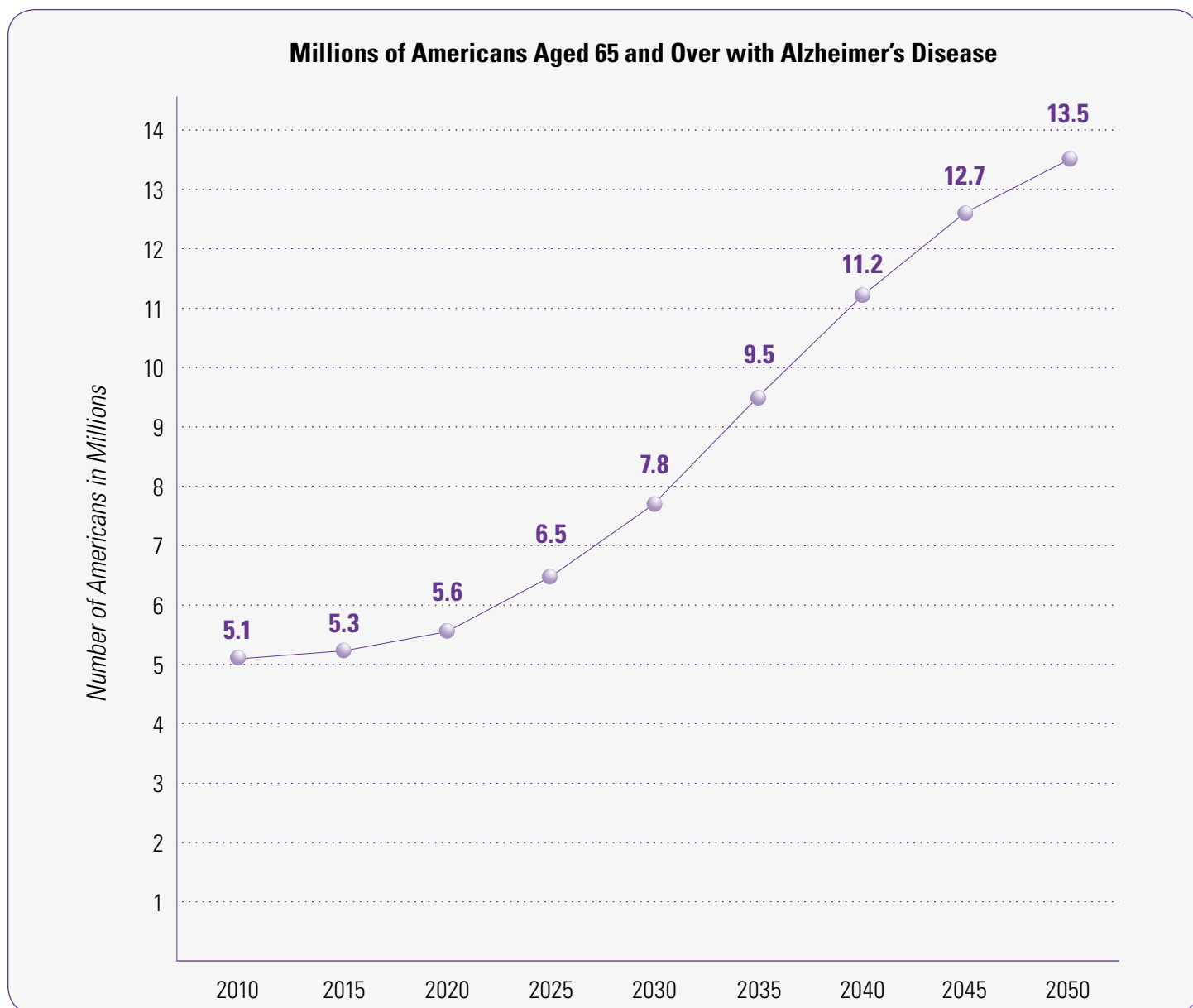
One in eight baby boomers will get the disease after they turn 65. At age 85 that risk increases to nearly one in two. And if they don't have it, chances are they will likely be caring for someone who does.

For many baby boomers, Alzheimer's was a disease they saw in their parents or grandparents. Not anymore. Alzheimer's disease is now *their* disease, *their* crisis, *their* epidemic.

“When she disappears into the bathroom and does not come out for an extended period of time, that is the signal that something is wrong. She is too proud and embarrassed to call for help, so she tries to take care of the situation herself. Of course, that makes the mess worse and more difficult for me because now I have to clean both her and the bathroom. Who on earth could ever have imagined the day would come when I would be changing the diapers of the woman who changed mine?”

— *Randy Sibbett, California*

The Truth about Alzheimer's that Every American Should Know



- 5.3 million Americans are currently living with Alzheimer's disease — 5.1 million of them aged 65 and over.
- One in eight Americans aged 65 and over has Alzheimer's. Nearly one in two aged 85 and over has the disease.
- Every 70 seconds, someone in America develops Alzheimer's.
- With the aging of the baby boomers, the number of Americans with Alzheimer's will likely reach 13.5 million in 2050 — and could be as high as 16 million.
- 10 million baby boomers will get Alzheimer's.
- In 2050, an American will develop Alzheimer's every 33 seconds.

Alzheimer's Is Devastating, Deteriorating and Debilitating

Alzheimer's disease is not just a little memory loss. It eventually kills you, but not before it takes everything away — slowly, gradually, painstakingly, **inevitably**.

This devastating, deteriorating and debilitating disease is the ultimate thief — thief of memories, thief of independence, thief of control, thief of time and ultimately thief of life. Alzheimer's robs people of all bodily functions and eventually their humanity. Day by day, Alzheimer's strips away individuality, autonomy and independence. It means the loss of anything and everything you have ever known.

“She has become fascinated with ‘the lady in the mirror.’ At first, she didn’t recognize this lady as her own reflection. It scared her that ‘the lady’ was mocking her by following her around and imitating everything she did.”

— Eugene Fields, Ohio

*Try to imagine not
being able to take care
of yourself.*

Try to imagine not being able to take care of yourself.

Can't dress yourself.

Can't shower yourself.

Can't go to the bathroom by yourself.

That's Alzheimer's disease.

The Truth about Alzheimer's that Every American Should Know



- An individual will live with the increasingly devastating, debilitating and destructive effects of Alzheimer's for many years.
- Most people survive an average of four to six years after a diagnosis of Alzheimer's — but many live for as long as 20 years with the disease.
- On average, 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.
- By age 80, 4 percent of Americans enter a nursing home. For people with Alzheimer's, 75 percent end up in a nursing home by age 80.

Alzheimer's Kills

Right now, we are losing the battle against Alzheimer's disease. Death rates for other major diseases — HIV, stroke, heart disease, prostate cancer, breast cancer — are declining. Our country's significant commitment to combat these conditions has saved lives.

*Alzheimer's is not just
a little memory loss.
It eventually kills,
but not before it takes
everything away.*

But for Alzheimer's disease, the federal government's efforts have been meager, and deaths are skyrocketing. The consequence is that over 80,000 Americans die each year of Alzheimer's — but only after a very long good-bye, only after years of suffering endured by individuals, family and friends. Today, there are no Alzheimer survivors — none.

“Dawn is coming. The sun will rise and peak. I now know my mother never will rise again. But still, every morning when the sun comes, I think maybe this will be the day she will know me. This will be the day I can tell her one last time that I love her, and she'll hear me. But in my heart, I know it's over.”

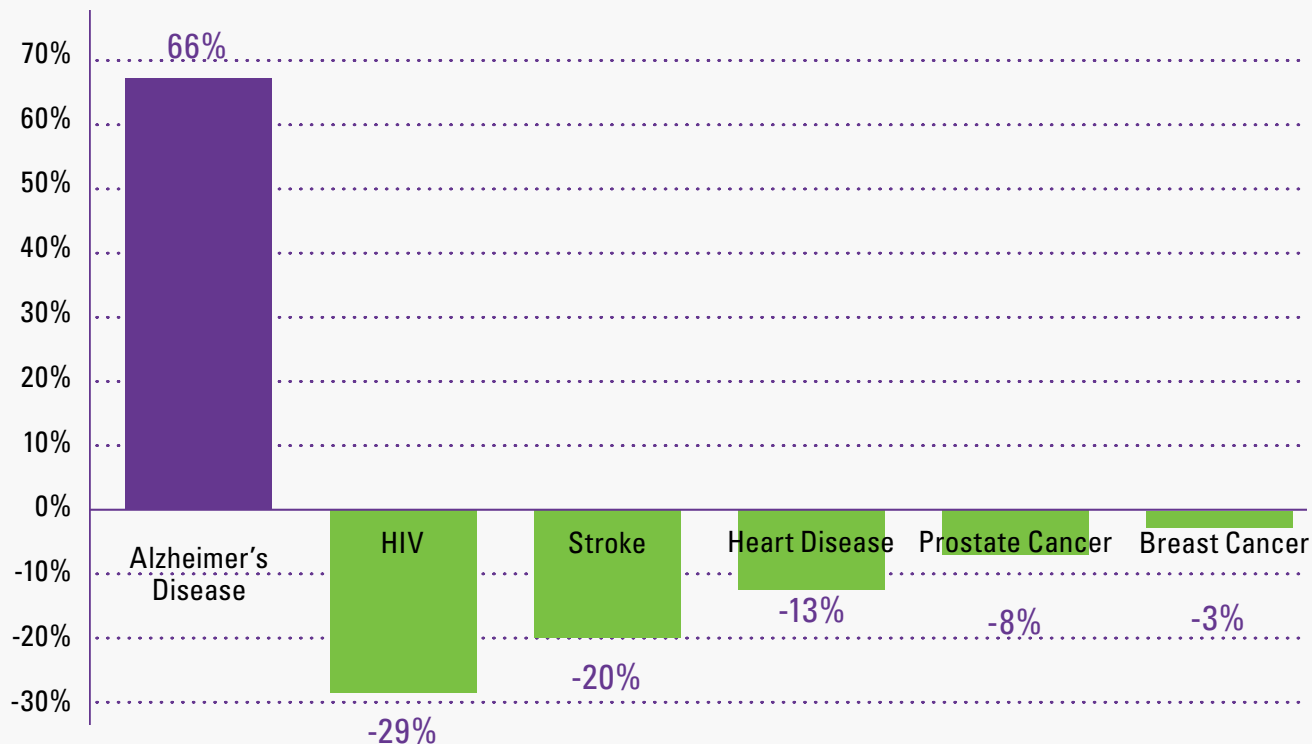
— Rob George, Texas

America means progress, solutions, results. But, Alzheimer's disease — the sixth-leading cause of death in America — remains the only one of the top 10 causes of death without an identified way to prevent it, cure it or slow its progression.

As the baby boomers begin reaching age 65, this means more deaths from Alzheimer's, more heartbreak. As the Baby Boom Generation ages, the situation is only going to deteriorate — as horribly as the disease itself — unless and until we demand a cure.

The Truth about Alzheimer's that Every American Should Know

Change in Number of Deaths, 2000–2008



Based on preliminary 2008 mortality data.

- Alzheimer's disease is the sixth-leading cause of death in the United States.
- The number of Americans that die each year from Alzheimer's disease has risen 66 percent since 2000.
- Each year, Alzheimer's kills more Americans than breast and prostate cancer **combined**.
- Alzheimer's is the only disease in the top 10 causes of death in America without a way to prevent it, cure it or slow its progression.
- Death rates for other major diseases, including the number-one cause of death (heart disease), have declined — thanks to the government's commitment to research.

Alzheimer's Is Heartbreaking

Alzheimer's doesn't just affect those with the disease. The toll Alzheimer's takes on caregivers is a burden financially, physically and emotionally. Just imagine the tragedy of watching your loved one, the light of your life, slowly disappearing day by day.

Yes, the financial cost — the cost of providing care for a loved one — is significant and often beyond what is affordable. And the hidden costs, the sacrifices that have to be made by the caregiver, are just as immense.

It's not just the people with Alzheimer's who suffer. It's also their caregivers.

But this is **nothing** next to the human cost, the toll Alzheimer's takes each and every day: lost jobs, lost savings, poor health, even lost lives due to the economic, emotional and personal strain caregivers endure.

“She'd throw temper tantrums at the dinner table, scream at me, take my toys or bang on glass mirrors trying to figure out why her reflection wouldn't answer her. My grandma's behavior was sometimes so bad, it was as if she were the child, even though she was 70 years older than me. As a young girl, sometimes I wasn't sure if her behavior was her actual personality or if it was Alzheimer's that made her be mean to me and steal my Beanie Babies.”

— Alissa Anderegg, California

The Truth about Alzheimer's that Every American Should Know



- In 2009, nearly 11 million Americans provided 12.5 billion hours of unpaid care to family members and friends with Alzheimer's disease.
- The value of this unpaid care totaled almost \$144 billion in 2009 — more than what Medicare and Medicaid spent combined on those with Alzheimer's.
- One-third of Alzheimer caregivers have been providing care for five years or more.
- Two-thirds of Alzheimer caregivers rate the emotional stress as high or very high.
- Alzheimer caregiving negatively affects health, employment, income and financial security.

Alzheimer's Is Bankrupting America

The graying of America means the bankrupting of America.

We are going to pay for Alzheimer's one way or the other — now or later.

Today, America spends \$172 billion caring for people with Alzheimer's and other dementias. With the aging of the baby boomers, Alzheimer's could bring this country to its financial knees. Costs will reach over \$1 trillion in 2050 — and that's not counting inflation.

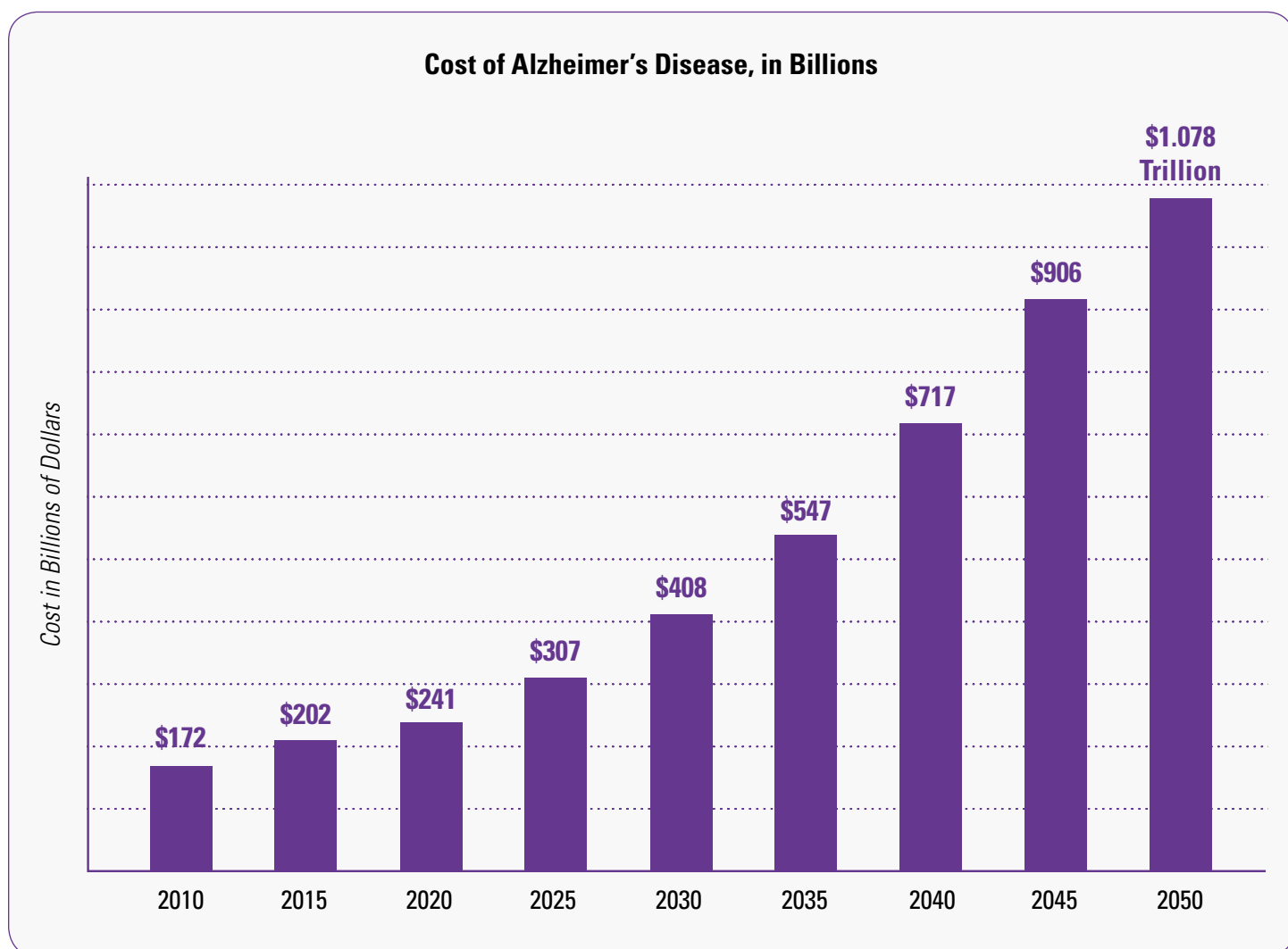
Almost half of all Alzheimer costs are paid by Medicare, where more than one in every six Medicare dollars is spent on someone with Alzheimer's disease. Curing Alzheimer's would help save Medicare.

“Since her diagnosis, my mother has steadily progressed and is no longer able to carry out simple tasks, such as washing dishes or putting on her own shoes. Recently, she has started using a cane to walk, and I find it hard to imagine the day when she will no longer be able to walk at all, feed herself or even recognize who I am. Yet I know that such a day will come.”

— Xuan Quach, California

We are going to pay for Alzheimer's one way or the other. The consequences of doing nothing will be continuing to pay for caring — and we should ensure more effective care for those with this devastating disease. But if we commit now to **curing** — to fund research that leads to a breakthrough — we can save billions of dollars. A commitment today to innovation, to finding a cure, will yield the savings of tomorrow.

The Truth about Alzheimer's that Every American Should Know



- In 2010, Alzheimer's and other dementias cost American society — families, insurers and the government — \$172 billion.
- In 2050, those costs will increase to over \$1 trillion (in current dollars).
- Over the next 40 years, Alzheimer's will cost America over \$20 trillion, enough to pay off the national debt and still send a \$20,000 check to every man, woman and child in America.
- Between 2010 and 2050, the costs to Medicare of caring for someone with Alzheimer's will increase over 600 percent — and the cost to families in out-of-pocket costs will grow more than 400 percent.
- A person with Alzheimer's disease on average, costs Medicare three times more and costs Medicaid nine times more than someone without the disease.

Where's the Treatment? Where's the Cure?

The federal government currently spends much less money on Alzheimer research, prevention and a cure than on other conditions such as cancer, heart disease and HIV — \$6 billion for cancer, \$4 billion for heart disease, \$3 billion for HIV/AIDS. But just \$480 million for Alzheimer's disease.

If you think finding a cure is expensive, consider the cost facing people living with the disease and those taking care of them.

The consequences are plain to see.

America has made progress against cancer, heart disease and HIV because of the federal government's commitment to combat them.

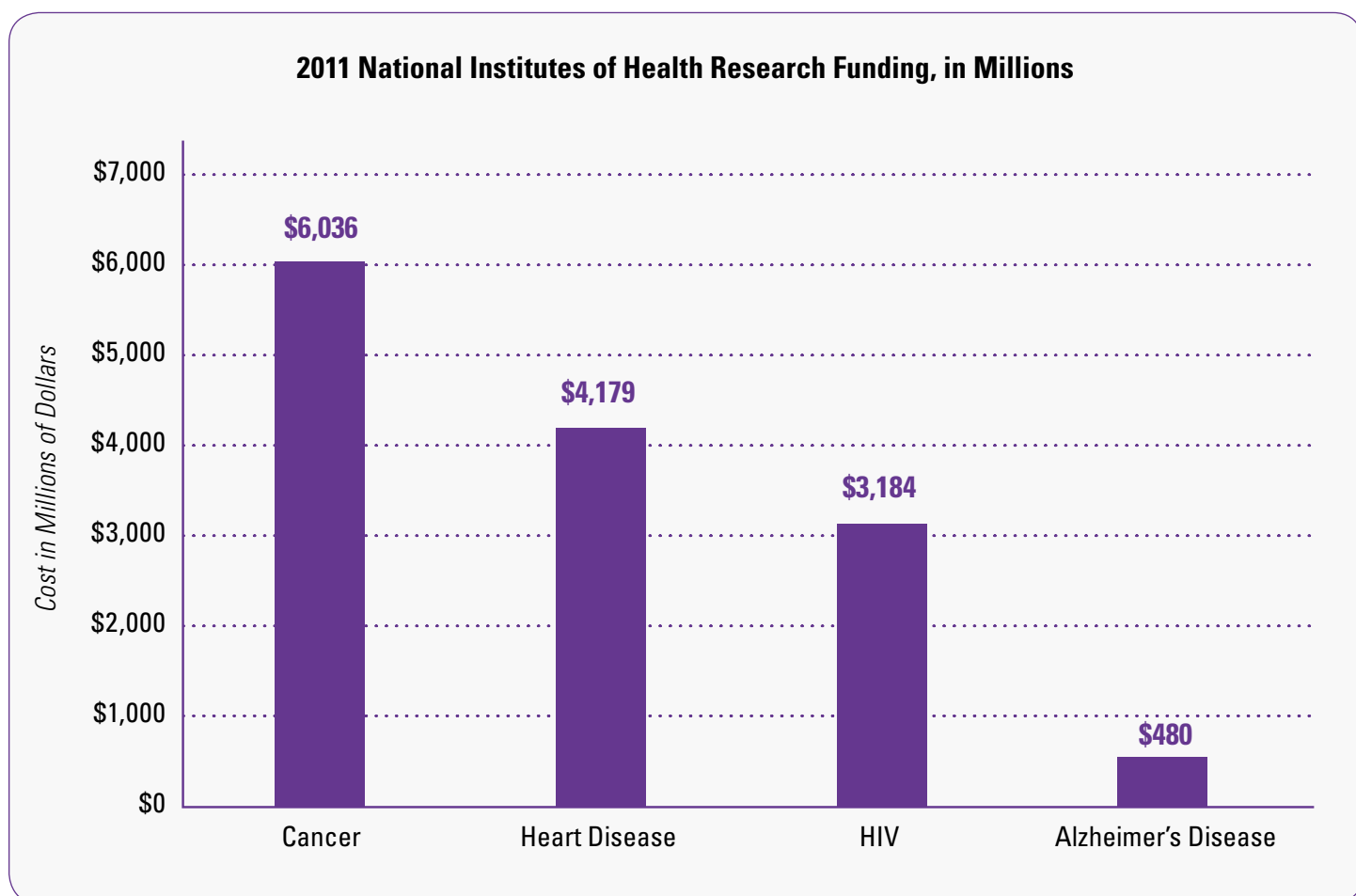
We can achieve the same results for Alzheimer's disease with a similar commitment to finding a cure. With such a commitment by the federal government, we can find ways to prevent, control and cure this heartbreaking disease.

"I began to realize I wasn't the gal I used to be. It was different inside my head. I would be talking with someone on the telephone, then hang up and ask myself, 'Who was that? What did we talk about?' My husband says he was shocked and knew something serious was going on when we returned from a vacation together, and I told him, 'I really had a great time in California. I'm so sorry you couldn't make it.'"

— Mary Ann Becklenberg, Indiana

We've already seen the consequences of underfunding. But there's more: we are at risk of losing a generation of scientists who are either choosing other fields or leaving research altogether. These brilliant minds are our greatest resource in this fight, and we should be applying them to our most difficult problems.

The Truth about Alzheimer's that Every American Should Know



- The National Institutes of Health spends over \$6 billion a year on cancer research, over \$4 billion on heart and cardiovascular disease research and over \$3 billion on HIV/AIDS research — with obvious payoffs in lives saved.
- But it spends only \$480 million on Alzheimer's research — and deaths are soaring.
- For every \$100 the government spends on Alzheimer research, it spends more than \$25,000 for care for people with Alzheimer's and other dementias.
- Research leading to treatments that delay onset of Alzheimer's by just five years would cut government spending on the disease by 45 percent.

Alzheimer's Disease Research: Genuine, Tangible, Hope

Despite the relatively low level of funding, Alzheimer's disease research has come so far, particularly in the last 10 years. With the cooperation of the medical and research communities, we are at a tipping point. We have the ideas, the technology and the will, but we do not have the commitment from the federal government. And we have reason for genuine and tangible hope that will fundamentally change the nature of the disease.

Scientists believe we are at a tipping point right now.

Every day brings us closer to a cure. An additional commitment through a public-private partnership could push us over the edge, make the difference and deliver the results.

A commitment to a thorough, heartfelt and innovative approach to finding results will give us significant returns on our investment, relief to those currently suffering from the disease and peace of mind to millions of baby boomers who will otherwise get the disease. And we can do it without the government increasing its deficit. It's how and where the government spends that matters.

We should not and cannot forget or neglect those who have this devastating and heartbreaking disease today or who will get the disease tomorrow. They need better care and better support services. And their struggling, loving families need more help.

For the first time in history, there is real hope in emerging science that we can overcome Alzheimer's disease and that the day is near when Alzheimer's does **not** need to be a death sentence.



“I want my husband back. I need him more than ever now, but he’s gone. I can’t go to him for advice. I can’t go to him for emotional support. He is just like a child. He is egocentric, can’t comprehend my feelings, can’t remember what I’ve been doing. I want someone to hold me and ease my fears like he used to. Or at least I want him to know that I’m a person like he is. But he doesn’t seem to get it anymore.

I’m dealing with Alzheimer’s disease. There is no hope that it will get better. It will keep getting worse. It will keep getting harder. It will keep costing more money. I will keep doing what I’m doing. And then he will die. I pray that I stay strong so that when he is gone, I don’t blame him for my failures or hate myself because I disrespected him in any way.”

— *Laura Jones, Florida*

Conclusion

When it comes to Alzheimer's disease, there are no Republicans or Democrats. It affects all of us, and with baby boomers aging, it is only going to get worse — and very fast.

We can all agree that we must find a cure for Alzheimer's.

Most of America's baby boomers will spend their retirement years either with Alzheimer's or caring for someone who has it.

If you think finding a cure is expensive, consider the cost facing people living with the disease and those caring for them. Think of the financial cost of round-the-clock care. Think of the human cost in emotional stress and strain. Think of the hidden costs — the sacrifices that have to be made every day. Think of the lost jobs, the lost savings, the lost lives.

Think of the devastation. Think of the heartbreak.



And then think of the hope. The hope for treatment. The hope for prevention. The hope for a cure.

The hope for families. The hope for the baby boomers who will soon get the disease.

Scientists believe we are on the verge of realizing that hope. The only unanswered questions are: Will we have the resources to push it over the edge and to make the difference? Will the federal government make the commitment to an innovative approach that will yield results, a return on our investment and the cure we so desperately need?

Our vision is a world without Alzheimer's disease. Let's make Alzheimer's disease a distant memory.

This is a fight we can win.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer 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.

Alzheimer's Association
National Office
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601-7633

Alzheimer's Association
Public Policy Office
1212 New York Ave., N.W., Suite 800
Washington, DC 20005-6105

1.800.272.3900
www.alz.org

©2011 Alzheimer's Association. All rights reserved.
This is an official publication of the Alzheimer's Association but may be distributed by unaffiliated organizations and individuals. Such distribution does not constitute an endorsement of these parties or their activities by the Alzheimer's Association.