



Alzheimer's Disease and Other Dementias

A Public Health Policy Issue for Idaho

Dr. Sarah Toevs
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Our Mission/Vision

Alzheimer's disease and other dementias will be identified as a **public health policy priority** in Idaho.

We will take a leadership role in educating legislators and the public about this growing health care issue and advocate for a **statewide strategic plan** to address it.



Our Steering Committee

Bruce Newcomb, Director, Boise State University, Government Relations

Amy Johnson, Assistant Director, Boise State University, Government Relations

Pam Catt-Oliason, Program Specialist, Idaho Commission on Aging

Joe Franco, Associate Director, Advocacy, National Alzheimer's Association

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A Looming Epidemic

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Alzheimer's forces workers to make difficult choice

As their work skills decline, they may face a decision whether to stay on the job or consider a change.

BY DIANE STAFFORD
MCCLATCHY NEWSPAPERS

The elevator door near her desk made too much noise to concentrate. The work day wasn't long enough to do her job. She had to stay up nights to meet deadlines.

Gwen Richards knew "the monster" had grabbed her. She knew that Alzheimer's disease had taken hold in her brain, just like it had in her mother's and older brother's.

"It was pretty easy for me to hide it for a while," said the 57-year-old Kansas City woman, who sometimes stayed up all night to finish the previous day's work from home.

"But immediately after I got the diagnosis of 'the monster' — that's what we call it

my family — I went in to my boss and told him that I needed to leave."

After 25 years at Yellow Roadway, Richards, a programmer, knew: "There was no way I could handle the technical stuff. I don't know what they could have done to accommodate me. There were deadlines. It wasn't good for me. I had to go."

Across the work world, employers are coming to grips with more employees like Richards, people who begin to show signs of dementia and deteriorating job performance.

At Harris, Rothenberg International, a provider of employee-assistance programs for corporate clients, there has been a 100 percent increase since 2009 in the number of calls for help dealing with employees who have Alzheimer's or with employees who are saddled with demanding caretaking responsibilities for a loved one.

"The recession is keeping some people at work long after they intended to retire because they have to work," said Randy

Martin, director of clinical services at Harris, Rothenberg. "A lot of people also want to keep working simply because of desire. Whatever the reason, employers are encountering more people with dementia in the workplace."

Like Richards, some employees realize what's happening and leave on their own, Martin said. But, "more often they hide it because they don't want to lose their jobs, or it's a head-in-the-sand kind of thing."

Eventually, employers are forced to deal with an emotional and touchy problem: They have to put people on notice that they're no longer meeting the basic requirements of their jobs.

"The nature of the job depends a lot on how the deficits are exposed and on how much an employer can adapt the job to accommodate the worker," said Michelle Niedens, spokeswoman for the Heart of America Alzheimer's Association.

See ALZHEIMER'S, B3



A Looming Epidemic

Frantic families demand help with Alzheimer's

The feds promise a plan for the burgeoning disease, including research and assistance for caregivers.

BY LAURAN NEERGAARD

THE ASSOCIATED PRESS

WASHINGTON — As her mother's Alzheimer's worsened over eight long years, so did Doreen Alfaro's bills: The walker, then the wheelchair, then the hospital bed, then the diapers — and the caregivers hired for more and more hours a day so Alfaro could

go to work and her elderly father could get some rest.

Alfaro and her husband sold their California house to raise money for her mother's final at-home care. Six years later, the 58-year-old Alfaro wonders if she eventually develops Alzheimer's, too. "What happens to my care? Where will I go?"

Dementia is poised to become a defining disease of the rapidly aging population — and a budget-busting one for Medicare, Medicaid and families. Now the Obama administration is developing the

first National Alzheimer's Plan.

"This is a unique opportunity, maybe an opportunity of a lifetime in a sense, to really have an impact on this disease," says Dr. Ronald Petersen of the Mayo Clinic, who chairs a committee that later this month begins advising the government on what that plan should include.

An estimated 5.4 million Americans have Alzheimer's or similar dementias. It's the sixth-leading killer. There is no cure; treatments only temporarily ease some symptoms. Barring a research break-

through, those numbers will worsen steadily as the baby boomers gray: By 2050, anywhere from 13 million to 16 million Americans are projected to have Alzheimer's, costing a \$1 trillion in medical and nursing home expenditures.

But that's not the full toll. Sufferers lose the ability to do the simplest activities of daily life and can survive that way for a decade or more, requiring years of care from family, friends or paid caregivers. Already a recent report

See ALZHEIMER'S, A6

A6 TUESDAY, SEPTEMBER 13, 2011

ALZHEIMER'S

CONTINUED FROM A1

finds that nearly 15 million people, mostly family members, are providing more than \$200 billion worth of unpaid care.

Thousands of those caregivers have turned out at public meetings since early August — and at a "telephone town meeting" organized by the Alzheimer's Association that drew 32,000 people — pleading for a national Alzheimer's strategy to bring changes.

They want primary care doctors trained to diagnose dementia earlier, describing how years of missed symp-

ptoms cost them precious time to make plans or seek treatment.

They demand to know why the National Institutes of Health spends about six times more on AIDS research than on Alzheimer's, when there are good drugs to battle back the HIV virus but nothing comparable for dementia.

Overwhelmingly, they ask for resources to help Alzheimer's patients live their last years at home without ruining their caregivers' own health and finances.

"Either you're rich and can afford \$25 an hour for care at home, or you send him to a facility. We're in the middle of the road," says

Shirley Rexrode of suburban San Francisco, whose 85-year-old father, Hsien-Wen Li, was diagnosed with Alzheimer's nearly three years ago.

Adult day care didn't work out — even at \$90 a day, the only place with an opening couldn't handle the behaviors of Alzheimer's. Rexrode's mother, Li's primary caregiver, already has suffered some depression.

"We just have to muddle through, but we don't know how long we can," Rexrode says.

And while Medicare will pay for doctor bills and medications, even getting to the doctor can be a hurdle. When her 89-year-old moth-

er with advanced Alzheimer's developed a urinary tract infection, Susan Lynch couldn't find a doctor willing to come to her parents' home in Fall River, Mass. Lynch flew there from her Gaithersburg, Md., home but couldn't carry her mother down the stairs. A private ambulance service didn't have an opening for weeks. Lynch wound up calling the town ambulance for a costly but Medicare-covered trip to the emergency room.

Federal health officials, who promise a first draft of the national plan by December, say they're getting the message.

"Folks desperately, des-

perately want to be able to provide the care themselves," says Donald Moulds, a deputy assistant secretary at the Department of Health and Human Services who oversees the project. "It's very, very hard work. Figuring out better mechanisms for supporting people who are trying to do that work is, one, the right thing to do."

It also may be cheaper for taxpayers. Nursing homes not only are pricier than at-home care, but many families only can afford them through Medicaid, the health care program for the poor. Another key, Moulds says, is better care coordination as Alzheimer's complicates the many other health

problems of aging.

But given the budget crisis, the big question is whether any anti-Alzheimer's strategy can come with enough dollars and other incentives attached to spur true change.

Moulds says U.S. families are telling him that any Alzheimer's plan must bring better understanding of a disease too often suffered in isolation.

"What I want to see is mainly awareness, awareness of this disease and what it does not only to the individual but also to the network of family and friends that are going to care for the person," says Alfaro, of Aptos, Calif.

FROM THE FRONT PAGE

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A Looming Epidemic



Newt Gingrich Testifies on Alzheimer's on Capitol Hill
with O'Connor, Kerrey, and Shriver

Date: March 25, 2009

Time: 10:30 AM

Location: Dirksen Senate Office Bldg, RM 106,
Washington, DC

A Looming Epidemic

National Alzheimer's Project Act Wins Congress' Approval

<http://alzheimersweekly.com/print/959>



Published on *Dementia & Alzheimer's Weekly* (<http://alzheimersweekly.com>)

[Home](#) > National Alzheimer's Project Act Wins Congress' Approval

National Alzheimer's Project Act Wins Congress' Approval

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Participants in The Alzheimer's Breakthrough Ride presented 110,000 petitions for passage of the National Alzheimer's Project Act. Washington, DC – In a huge boost to the dementia community, the full U.S. Congress approved passage of the National Alzheimer's Project Act (S. 3036, H.R. 4689), or NAPA for short. With the support of both the Senate and the House of Representatives, this is a significant step forward in the fight against all dementias, including the most common one, Alzheimer's disease.

The National Alzheimer's Project Act (NAPA) provides an essential framework for the development of a national strategic plan. Championed in the House by the co-chairs of the bipartisan Congressional Task Force on Alzheimer's, Representatives Ed Markey (D-Mass.) and Christopher Smith (R-NJ), passage of this legislation signals a recognition from the nation's leaders that a coordinated federal approach is necessary to confront one of America's most feared and costly diseases. "When America has a game plan, America wins. Passage of this bill means we will help ensure that the federal government better coordinates all of the research and clinical programs dealing with Alzheimer's, which is now the seventh leading cause of death in the United States," said Representative Edward J. Markey (D-Mass.). This legislation requires a plan for beating Alzheimer's and represents an important step forward in our country's efforts in this area."

"The passage today of the National Alzheimer's Project Act is a huge step forward in our battle against the crisis of Alzheimer's disease," Smith said. "With the incredible devastation of over five million Americans afflicted with Alzheimer's disease at an estimated cost of over \$170 billion – numbers expected to skyrocket in coming years without effective interventions – we need to be sure we are doing everything possible to reverse the course of this disease. By requiring the development of a coordinated, integrated national plan to address Alzheimer's, NAPA will provide the framework to accelerate the development of efficacious care and treatments.

Building on the work of The Alzheimer's Study Group, an independent, bipartisan panel created to evaluate the government's current efforts to combat the disease, NAPA will lead to the creation of a national strategic plan to overcome the dementia epidemic. It would also establish an interagency council to work with the Health and Human Services Secretary to give a full assessment of what needs to be done to address the threat of dementia on multiple fronts including care, research and support. NAPA would ensure strategic planning and coordination of the fight against dementias such as Alzheimer's across the federal government as a whole. "Today there are more than 5 million Americans living with this disease and this number is expected to soar to as many as 16 million by mid-century. This bipartisan legislation creates a new, much needed framework for addressing this public health threat," said Harry Johns, President and CEO of the Alzheimer's Association.

"Passage of NAPA is a hard earned win for the hundreds of thousands of Alzheimer advocates across the nation who have joined with the Alzheimer's Association in making this a top legislative priority for the 111th Congress. By sending this bill to President Obama's desk, this Congress will be remembered by the Alzheimer community for launching a critical effort to confront the grave public health threat of Alzheimer's."

Dementias such as Alzheimer's don't just affect individuals – they impact entire families. For the estimated 19 million caregivers, dementia can take be costly, representing a serious threat to their finances, job security, and health. But beyond the human impact on families, the economic burden – with total care costs escalating from \$172 billion today to more than \$1 trillion by 2050 – is significant as well. NAPA is fundamental to turning the tide for not only millions of families but also for the fiscal foundation of the country.

Maria Shriver, one of the nation's leading advocates for families struggling with dementias such as Alzheimer's, has worked with the Alzheimer's Association to shine a spotlight on the disease, including the recent release of The Shriver Report: A Woman's Nation Takes on Alzheimer's, which explored the disease's impact on women. "The passage today of the National Alzheimer's Project Act is a momentous legislative victory for the millions of American families profoundly affected by this devastating disease, and the millions more who will be in the future," said Maria Shriver, First Lady of California. "Thanks to the bipartisan action of Congress and the leadership of the Alzheimer's Association, the United States is on its way to having a national plan so our country will be prepared to handle this national emergency and advance ourselves toward a cure."

Dementia advocates such as The Alzheimer's Association, along with millions of families, are urging the President to sign this legislation into law, before January 2011, when the first wave of baby boomers begin turning 65 and face higher risk for developing dementia.

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Idaho and Alzheimer's Disease

What Idahoans are saying

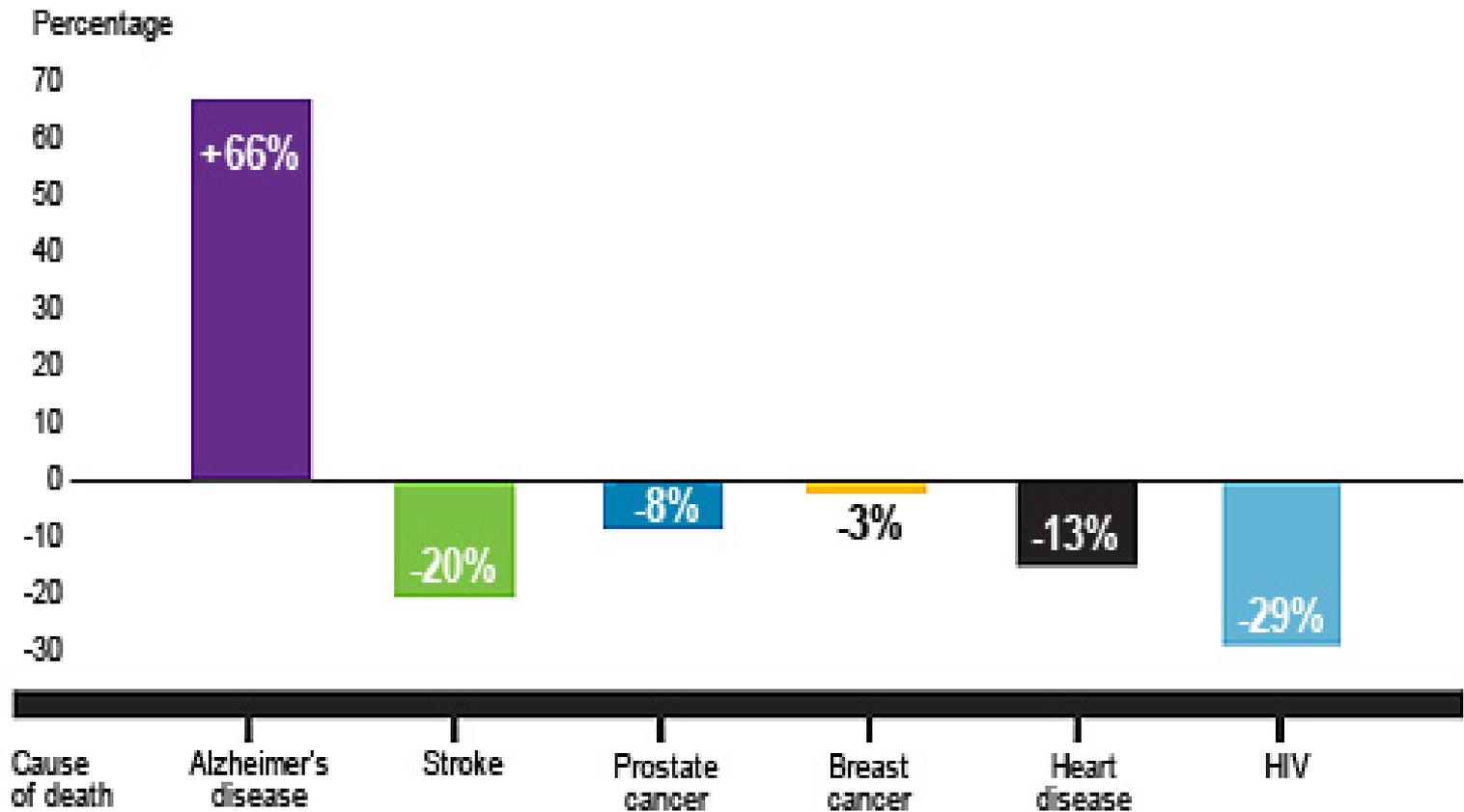
“It is such a devastating disease as it takes years to die and caregivers are left mentally and physically exhausted and in financial ruin.”

– Coeur d'Alene, ID

“Support the caregivers and you can keep Alzheimer's patients safely at home with loved ones – and at a much reduced cost.” – Athol, ID

Mortality and Alzheimer's Disease

Changes in Selected Causes of Death, 2000-2008



Idaho and Alzheimer's Disease

National Average Death Rate (per 100,000) due to AD =

25

Idaho's Average Death Rate (per 100,000) due to AD =

28



Our Strategy for Developing a Statewide Plan

1. Awareness & Education Campaign
2. Data Collection/Community Input
3. Legislative Agenda



What We've Done to-Date

- ✓ Presented to House and Senate H&W Committees (March 2011)
- ✓ Provided Keynote Speakers at Alzheimer's and Caregiver Conferences around the state (Oct-Nov)
- ✓ Working toward obtaining a grant from AARP to assist us in developing a statewide plan
- ✓ Introduced IAPG to Idaho Commission on Aging (Steering Committee Member) and Department of Health and Welfare Medicaid Bureau on Long-term Care



Our Next Steps

- ❑ Awareness Campaign
 - Expand Speaker's Bureau → "Brain Health"
 - Continue to Expand Statewide Email List
- ❑ Data Collection/Community Support for development of a statewide plan
 - Analyze Data (July 2012)
 - Write Plan/Prioritized Recommendations (Aug 2012)
- ❑ Legislative Agenda
 - Recruit Legislative Champions
 - Consider Requesting a Concurrent Resolution in support of Grant Applications (both Federal and private) and working with state agencies during plan implementation

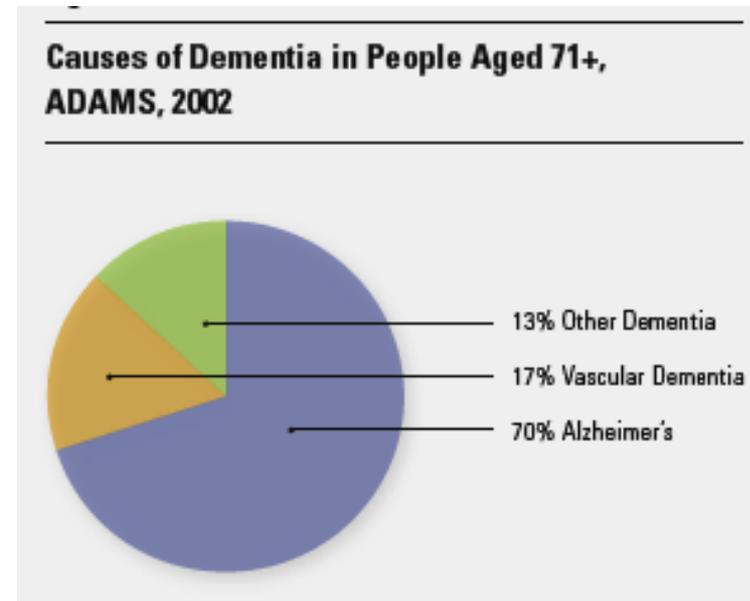


What Is Alzheimer's Disease?

Dr. Troy Rohn
Boise State University
Department of Biological Sciences

What is Alzheimer's Disease?

- ❖ Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills. Another word for these symptoms: *Dementia*
- ❖ Greatest risk factor: Advancing age

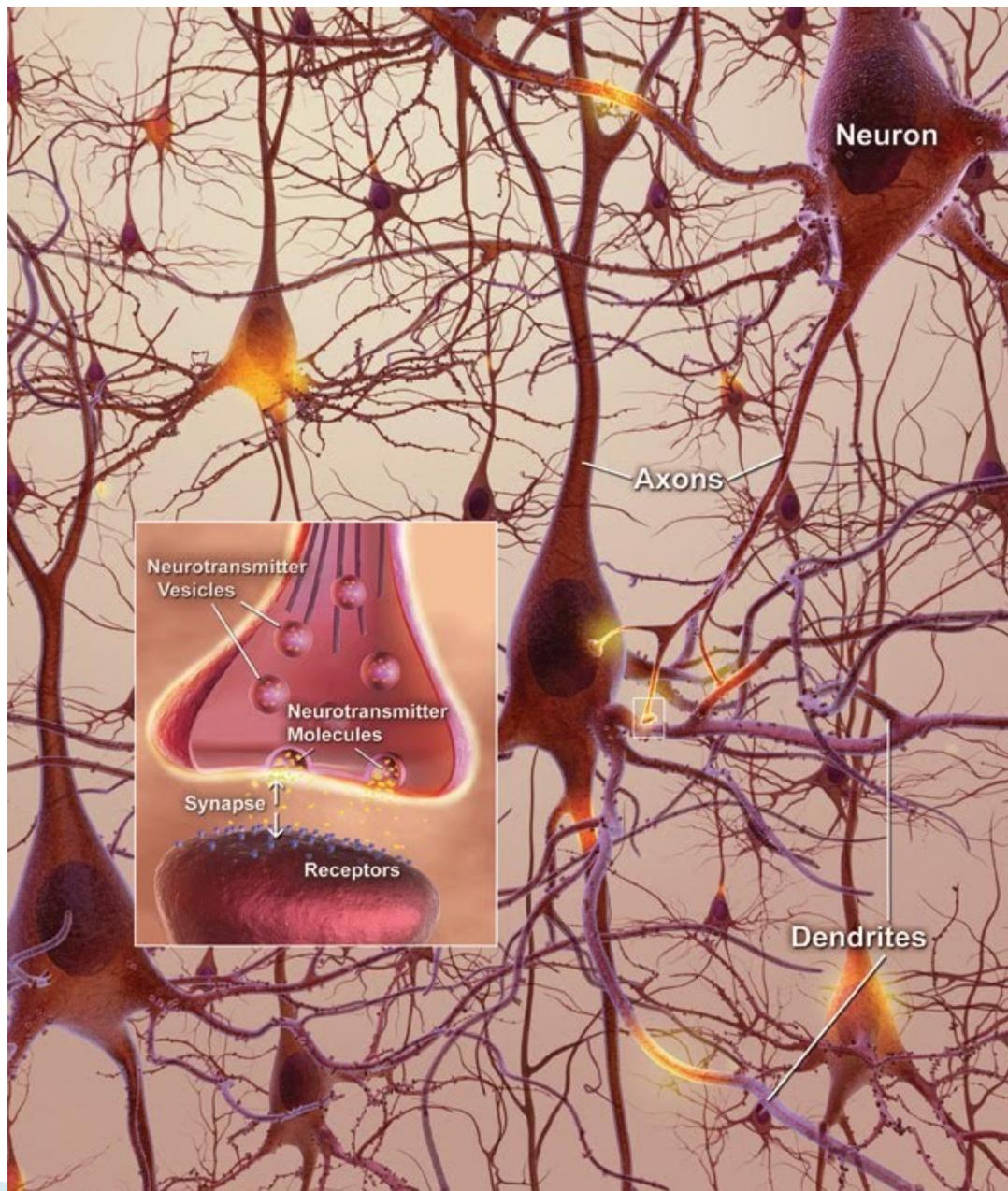


- ❖ Neurodegenerative disease characterized by abnormalities in the brain affecting neurons

Inside the Human Brain

Neurons

- ❖ The brain has billions of neurons, each with an axon and many dendrites.
- ❖ To stay healthy, neurons must communicate with each other and carry out metabolism.
- ❖ AD disrupts both of these essential jobs.



Molecular causes of AD

In AD, there is a profound loss of neurons

- ❖ The one over-riding pathological feature associated with AD is a loss of neurons in the brain areas associated with memory or cognitive functions.
- ❖ This loss of neurons is reflected as a pronounced loss of brain mass associated with AD brains.
- ❖ Neurons are incapable of dividing, so once they are lost, they are lost forever.

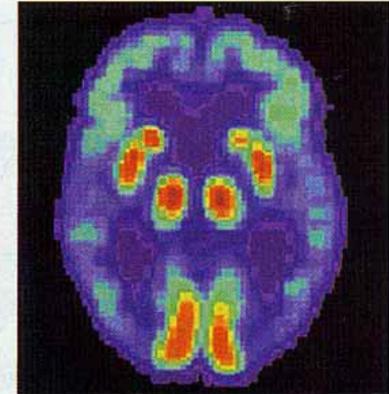
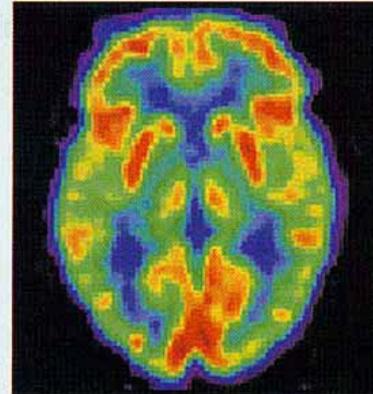
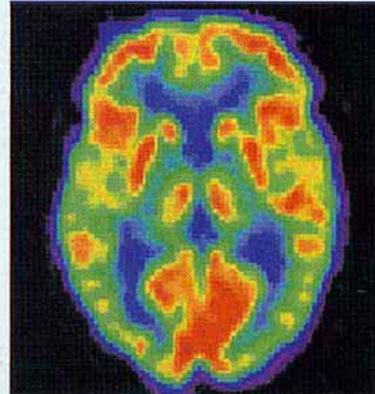
AD causes functional and structural changes in the brain

PET Scan

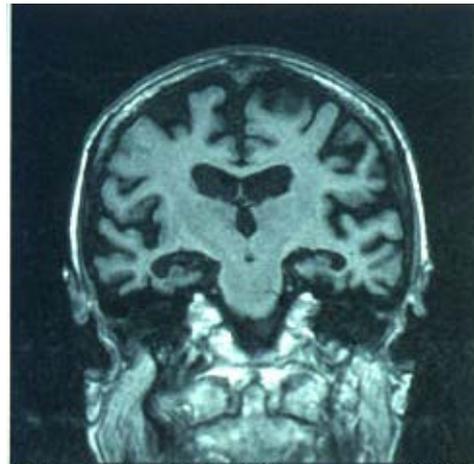
20 yr old

80 yr old normal

AD

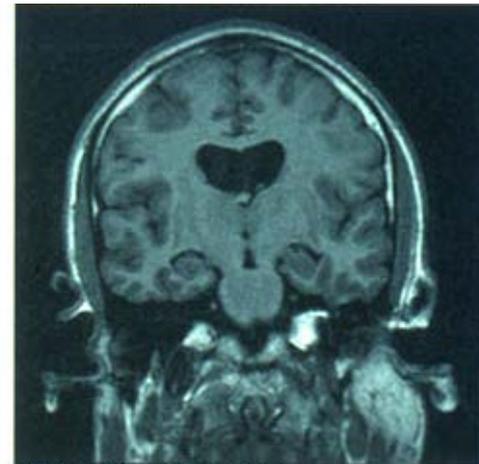


MRI



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Brain with A.D

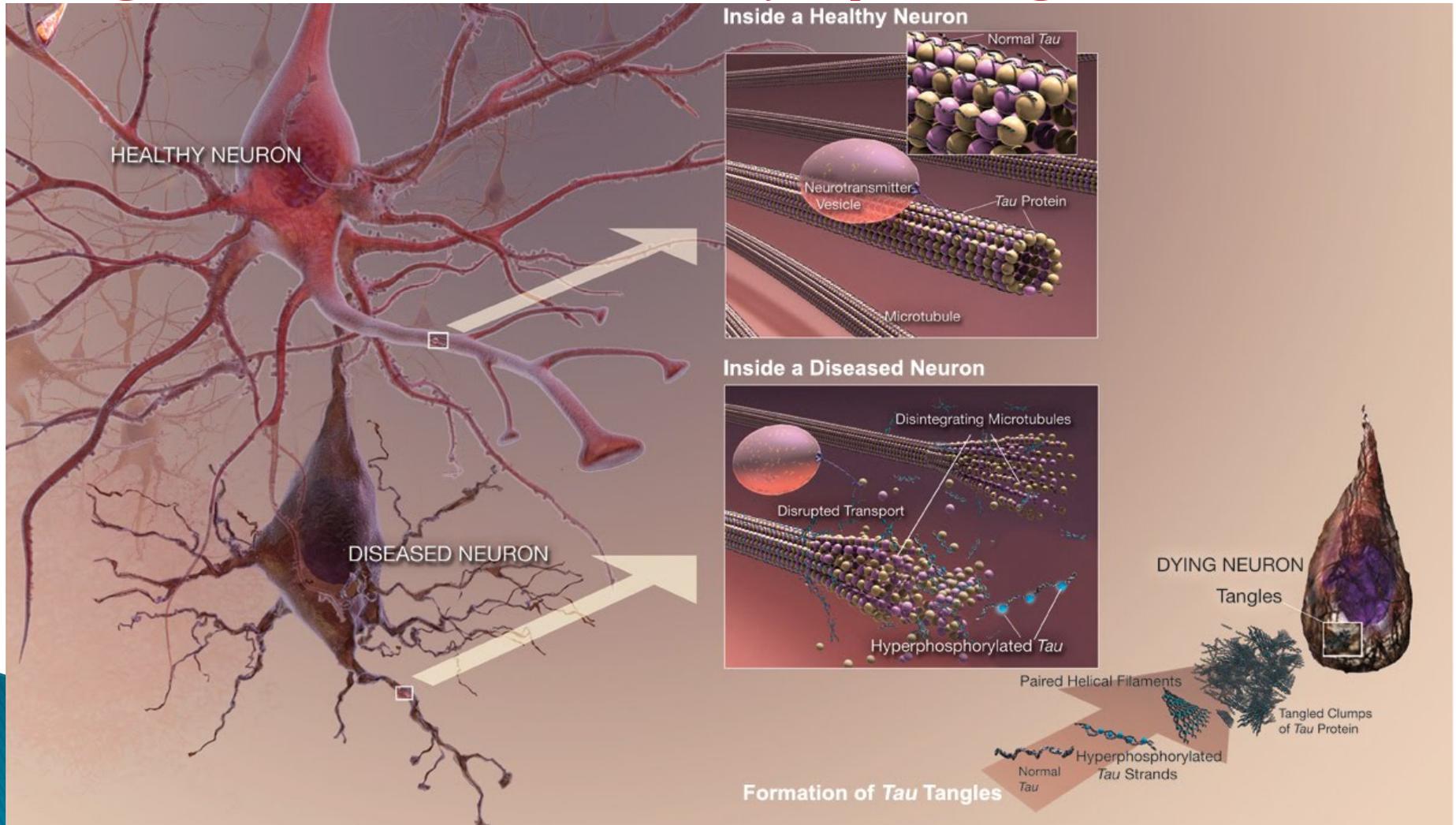


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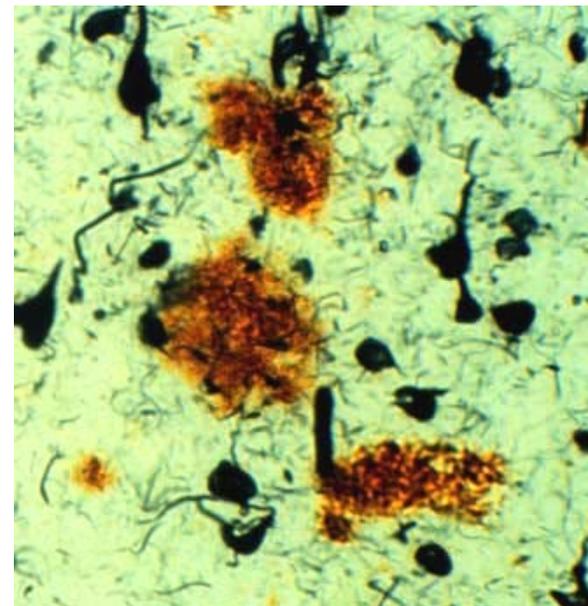
Normally Aged Brain

AD is characterized by several structural abnormalities in the brain

Tangles are one of the two major pathological features

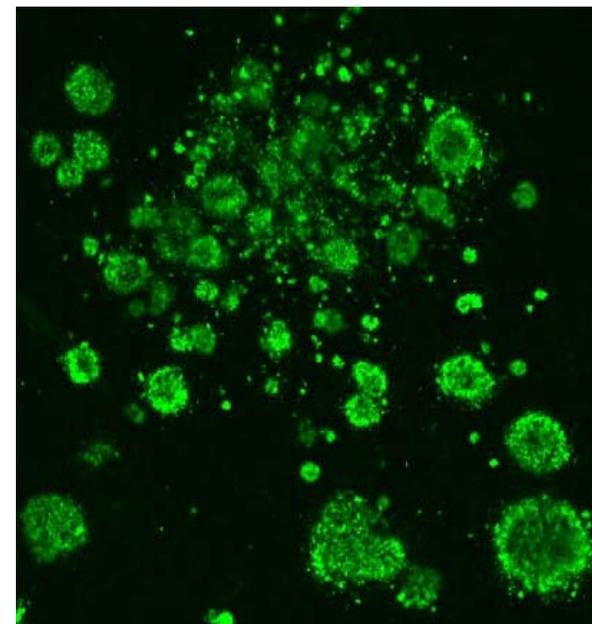


The other major pathological finding in the AD brain are senile plaques



What is beta-amyloid?

- ❖ It is the toxic protein fragment that is the major suspect in AD. Beta-amyloid accumulates into the characteristic amyloid plaques that distinguish the brains of people who die with AD.



Beta amyloid hypothesis

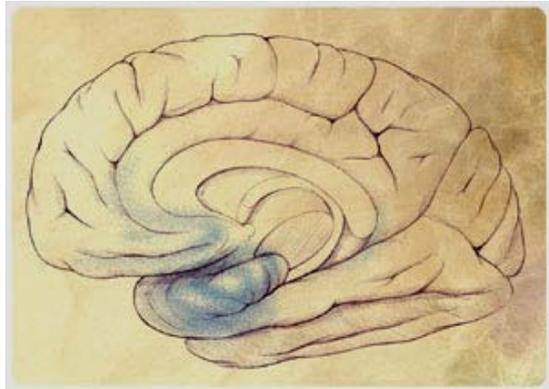
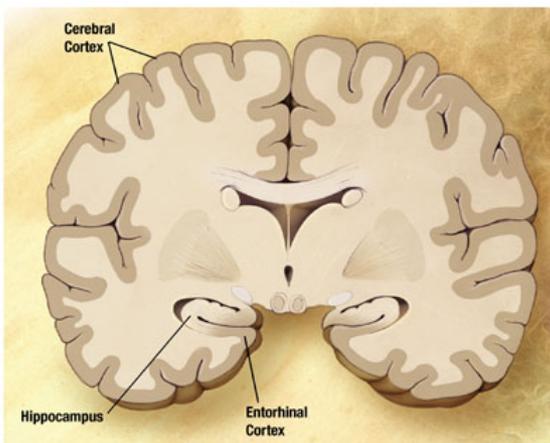
Beta amyloid → Plaques → Tangles



Cell death and symptoms

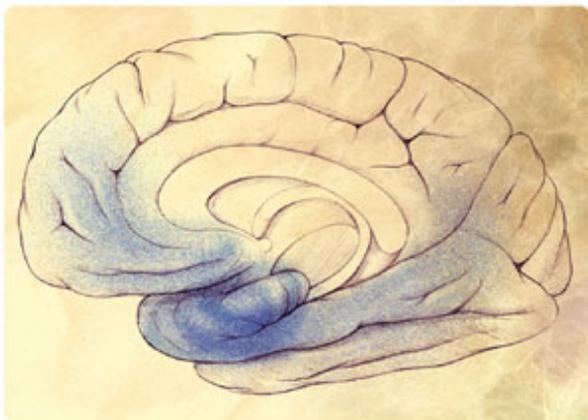
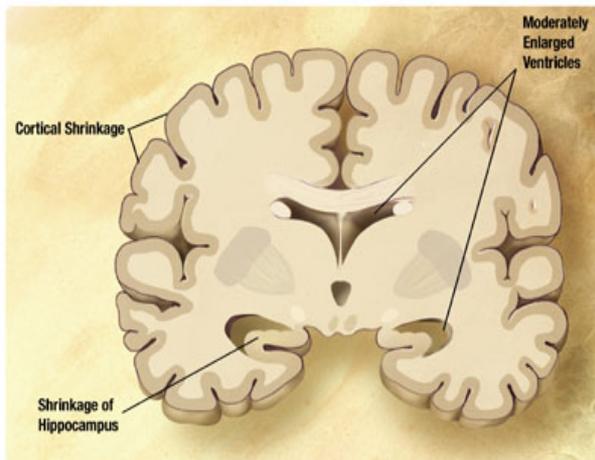
AD and the Brain

Preclinical AD



- ❖ Signs of AD are first noticed in the entorhinal cortex, then proceed to the hippocampus.
- ❖ Affected regions begin to shrink as nerve cells die.
- ❖ Changes can begin 10-20 years before symptoms appear.
- ❖ Memory loss is the first sign of AD.

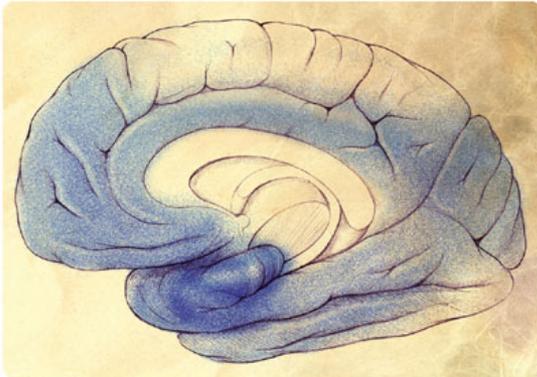
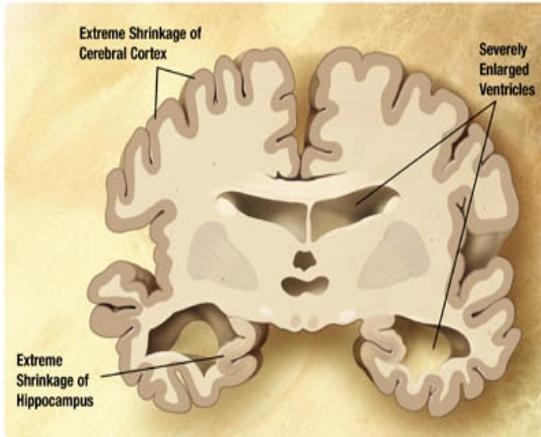
Mild to Moderate AD



AD and the Brain

- ❖ AD spreads through the brain. The cerebral cortex begins to shrink as more and more neurons stop working and die.
- ❖ *Mild AD signs* can include memory loss, confusion, trouble handling money, poor judgment, mood changes, and increased anxiety.
- ❖ *Moderate AD signs* can include increased memory loss and confusion, problems recognizing people, difficulty with language and thoughts, restlessness, agitation, wandering, and repetitive statements.

Severe AD



AD and the Brain

- ❖ In severe AD, extreme shrinkage occurs in the brain. Patients are completely dependent on others for care.
- ❖ Symptoms can include weight loss, seizures, skin infections, groaning, moaning, or grunting, increased sleeping, loss of bladder and bowel control.
- ❖ Death usually occurs from aspiration pneumonia or other infections. Caregivers can turn to a hospice for help and palliative care.

Current Research Goals

- ❖ Early detection and prevention
- ❖ Provide disease modifying treatments, i.e., those that attack beta-amyloid and tangles
- ❖ Preventative therapy that delays the onset of AD symptoms by 3.5 years, would reduce AD prevalence by 1/3.
- ❖ Delaying AD by six years would save families between \$150,000 and \$300,000, and allow affected individuals to live out their life at home.
- ❖ Provide education to community about healthy brain strategies including mental and physical exercises.



Opportunities and Impact in Idaho

Dr. Sarah Toevs
Boise state University
Center for the Study of Aging



IDAHO ALZHEIMER'S
PLANNING GROUP

Opportunities in Idaho

To improve the spectrum of prevention, diagnosis, treatment, and caregiver support services for Alzheimer's disease and other dementias.

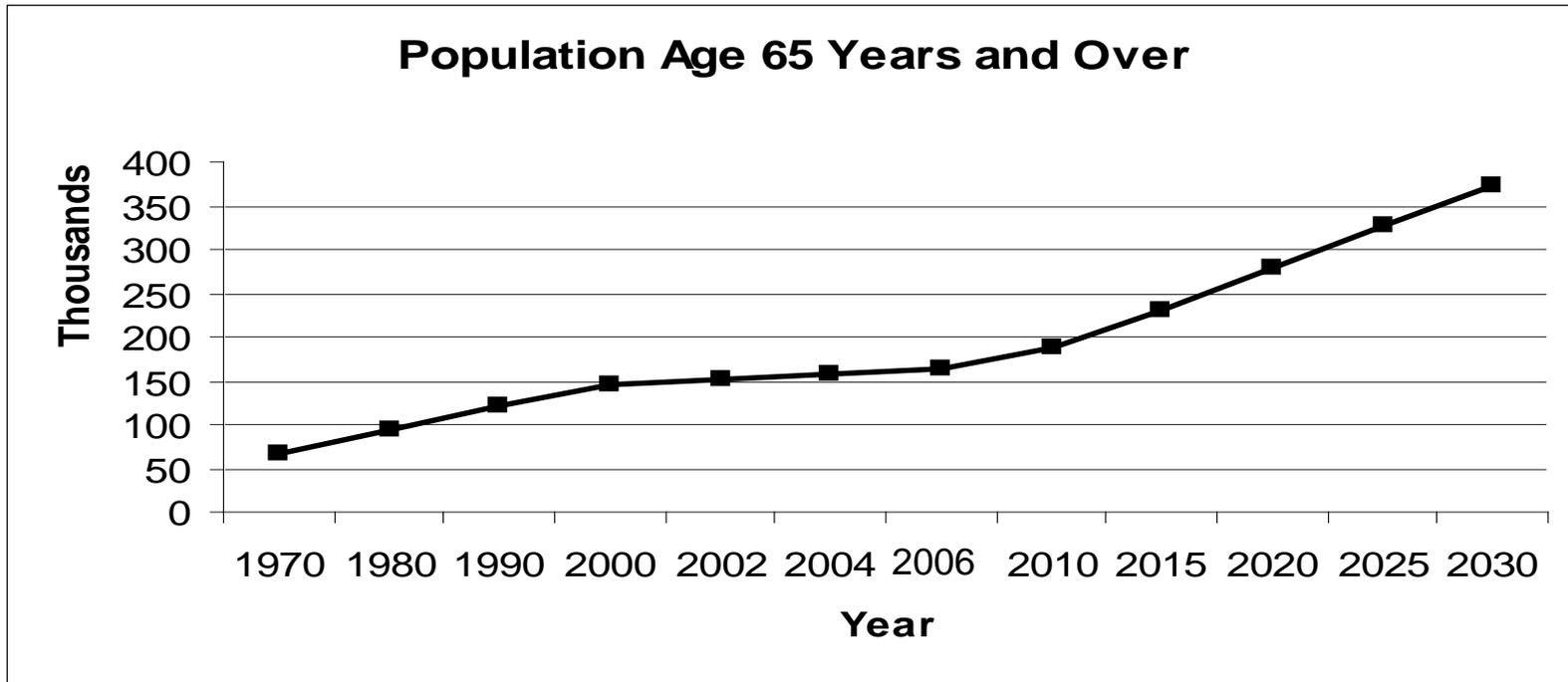
Opportunities in Idaho

- ❖ Medicaid Home and Community-based Services
- ❖ Idaho Home Choice Project
 - ❖ Medicaid Money Follows Person
- ❖ 2011 Medicaid Managed Care Plan (56-263 Idaho Code)
 - ❖ dual eligibility and chronic disease
 - ❖ improve coordination
 - ❖ improve health outcomes
 - ❖ eliminate duplicative practices
- ❖ Idaho Commission on Aging
 - ❖ Aging and Disability Resource Center (ADRC)

Opportunities in Idaho

- ❖ Research
 - ❖ Delay onset of disease
- ❖ Monitoring and Evaluation
 - ❖ Idaho Behavior Risk Factor Survey (BRFSS)
 - ❖ Cognitive Health and Caregiver Panels
- ❖ Development of a statewide plan for Alzheimer's disease and other dementias
 - ❖ Maximize caregiver resource
 - ❖ Avoid duplication of services
 - ❖ Enhance quality of life

Idaho Demographics



- ❖ Oldest Old (85 +) fastest growing segment
 - ❖ 18,057 in 2000
 - ❖ 23,384 in 2006
 - ❖ 47,000 by 2030

Impact on Idaho

- ❖ Incidence of Alzheimer's disease in Idaho
 - ❖ 26,000 – 32,000 people
- ❖ Projected to **double** by 2025
 - ❖ 52,000 – 64,000 people
- ❖ 73,000 informal caregivers
 - ❖ Providing over \$900 million of unpaid care

Impact on Idaho

- ❖ Medicaid primary payer of long term care expenditures
- ❖ Estimated cost of care: \$75,000/year*
 - ❖ Semi-private room in skilled nursing facility
- ❖ Impact of lost wages for caregivers

* 2009 Genworth Cost of Care Survey,
http://www.genworth.com/content/etc/medialib/genworth_v2/pdf/ltc_cost_of_care.Par.8024.File.dat/cost_of_care.pdf

Impact of a State Plan

- ❖ Integrate management of Alzheimer's disease and other dementias into current initiatives
- ❖ Bend cost curve of the disease by attacking it comprehensively
 - ❖ Support for informal caregivers
 - ❖ Delay onset through early intervention



Opportunities

- ❖ Idaho Alzheimer's Planning Group
- ❖ Concurrent Resolution
- ❖ Legislative Champion

Thank you.