

# From labels to legacy: deepening our understanding and caring for dementia

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Thanks to the Alzheimer Society of Canada



# Labels – “timely” diagnosis of what and for what purpose?

- Dementia
- Alzheimer’s
- Mild Cognitive Impairment
  - Pre
  - Early
  - Late
- Preclinical or symptomatic Alzheimer's
- Subjective Cognitive Impairment
- **Aging Associated Cognitive Challenges**

# Dementia is a changing label

Japan and Asia from Chiho to Ninchisho

American psychiatry Major Neurocognitive  
Disorder



Article

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# Government, professional and public efforts in Japan to change the designation of dementia (*chiho*)

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Dementia

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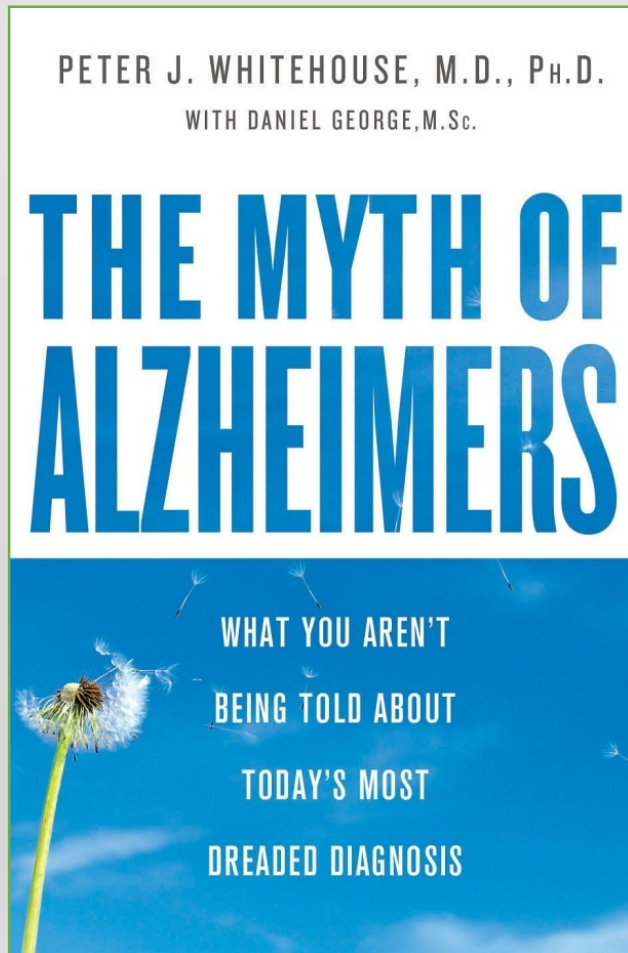
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Alzheimer's is an outmoded  
concept, maybe even a  
cognitively challenged one

G7 process is ending ("curing") Alzheimer's  
disease as a label by rightfully focusing on  
broader concept of dementia

# What is the Myth of Alzheimer's?



- Alzheimer's is heterogeneous i.e. not a single disease
- Alzheimer's is related to severe brain aging – perhaps the same processes

## Implications

- Cure or cures will be perhaps impossible, especially practically
- Care, community, prevention and public health will be key

[www.themythofalzheimers.com](http://www.themythofalzheimers.com)

# Alzheimer's Language Games

## Is it "just" aging?

Reflection and Reaction

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### Organising the language of Alzheimer's disease in light of biomarkers



Criteria for Alzheimer's disease dementia have served clinicians remarkably well for the past 25 years despite the fact that they predate knowledge of biomarkers, quantitative neuroimaging, other dementias of late life, and the amyloid hypothesis.<sup>1</sup> Both probable and possible diagnoses of Alzheimer's disease define advanced disease and are highly accurate in that they are strongly correlated to neuropathological changes seen at post mortem.

for typical Alzheimer's disease, which is further characterised as dementia or prodromal Alzheimer's disease. The definition of prodromal Alzheimer's disease is nearly identical to the criteria used in clinical trials and the Alzheimer's Disease Neuroimaging Initiative for "mild cognitive impairment due to Alzheimer's disease" except for the biomarker requirement. If the memory impairment is absent, then the diagnosis could be atypical Alzheimer's disease dementia, mild

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4422(10)70246-5

See Online/Position Paper  
DOI:10.1016/S1474-  
4422(10)70223-4



# Asymptomatic Alzheimer's disease – Reisa Sperling (but “its aging”)

## Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging and the Alzheimer's Association workgroup

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Kristine Yaffe<sup>p</sup>, Maria C. Carrillo<sup>q</sup>, Bill Thies<sup>q</sup>, Marcelle Morrison-Bogorad<sup>r</sup>, Molly V. Wagster<sup>r</sup>,  
Creighton H. Phelps<sup>r</sup>

Neuropathology – not definite but  
“disengaged” –Brad Hyman but “it’s  
aging”

**National Institute on Aging–Alzheimer's Association guidelines for the  
neuropathologic assessment of Alzheimer's disease**

**Co-chairs:** Montine and Hyman

**Members:** Beach, Biglo, Cairns, Dickson, Duyckaerts, Frosch, Masliah, Mirra, Nelson,  
Phelps, Schneider, Trojanowski, and Vinters

DRAFT

Biomarkers are unproven in many ways but being promoted

## Amyloid Imaging 101: Why, What, When, and for Whom

**Keith A. Johnson, MD**  
Co-Leader, Neuroimaging Program  
Massachusetts Alzheimer's Disease  
Research Center  
Professor of Radiology  
Harvard Medical School  
Boston, Massachusetts

## Lilly Backs Lawsuit Against CMS Over its Alzheimer's Diagnostic Drug

ARTICLE

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25



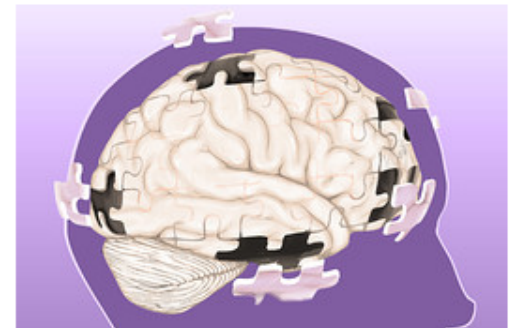
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By ED SILVERMAN

Nearly a year ago, the Centers for Medicare & Medicaid Services denied coverage for an [Eli Lilly](#) LLY +0.43% imaging agent to be used in diagnosing Alzheimer's. In reaching **its decision**, CMS cited a lack of evidence that the agent, called Amyvid, could improve health outcomes. As a result, CMS greatly narrowed the potential use of the agent, dealing Lilly a significant setback.



— Getty Images/Universal Images Group

Now, Lilly is fighting back.

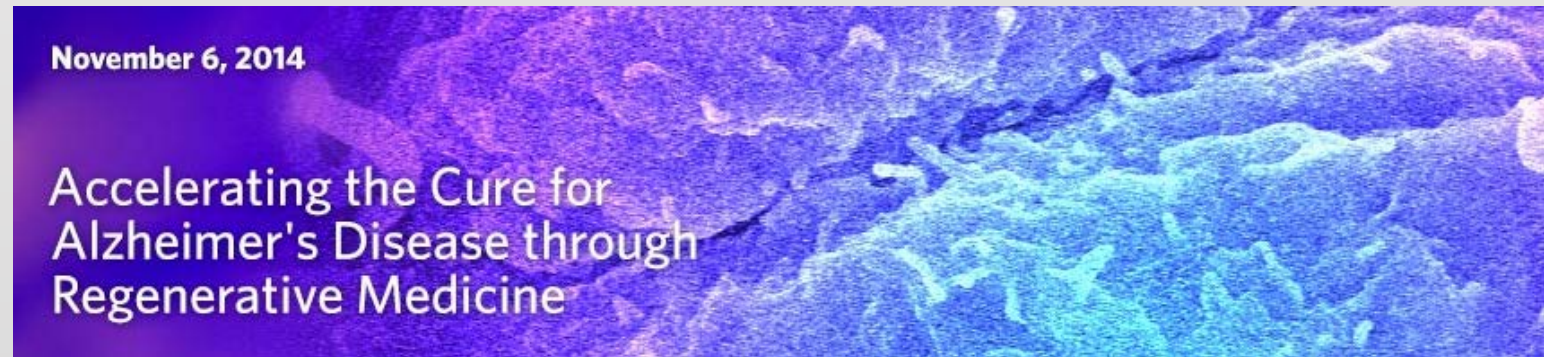
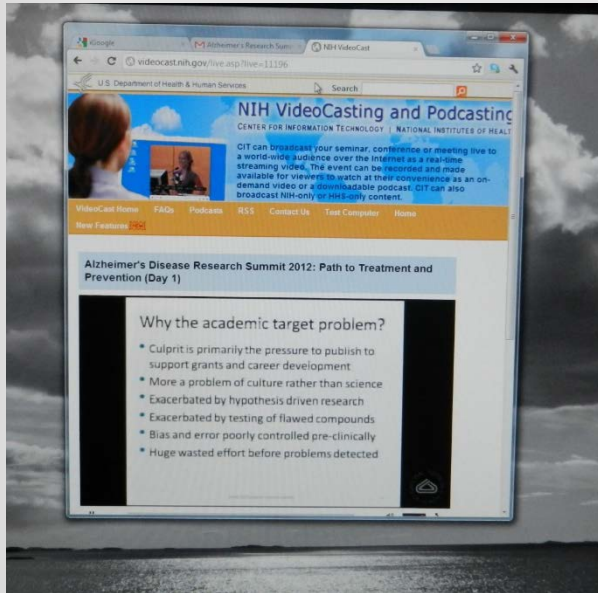
Basic science is  
Alzheimer's/dementia is in  
trouble –scientifically and morally

Mice get Mouseheimer's disease, not Alzheimer's disease

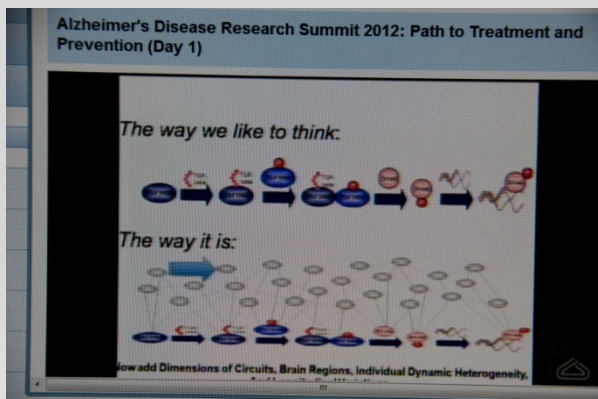
Problems of replicability

Problems of fame and fortune

# Alzheimer's Disease Research Summits NIH May 2012 and Duke November 6, 2014 Cure or even effective treatment by 2020?



Nov. 6 conference at Duke will allow both national experts and concerned laypeople to catch up on the use of stem cells in Alzheimer's research, a direction that is showing promise.



Care is not something we only do  
while waiting for a cure

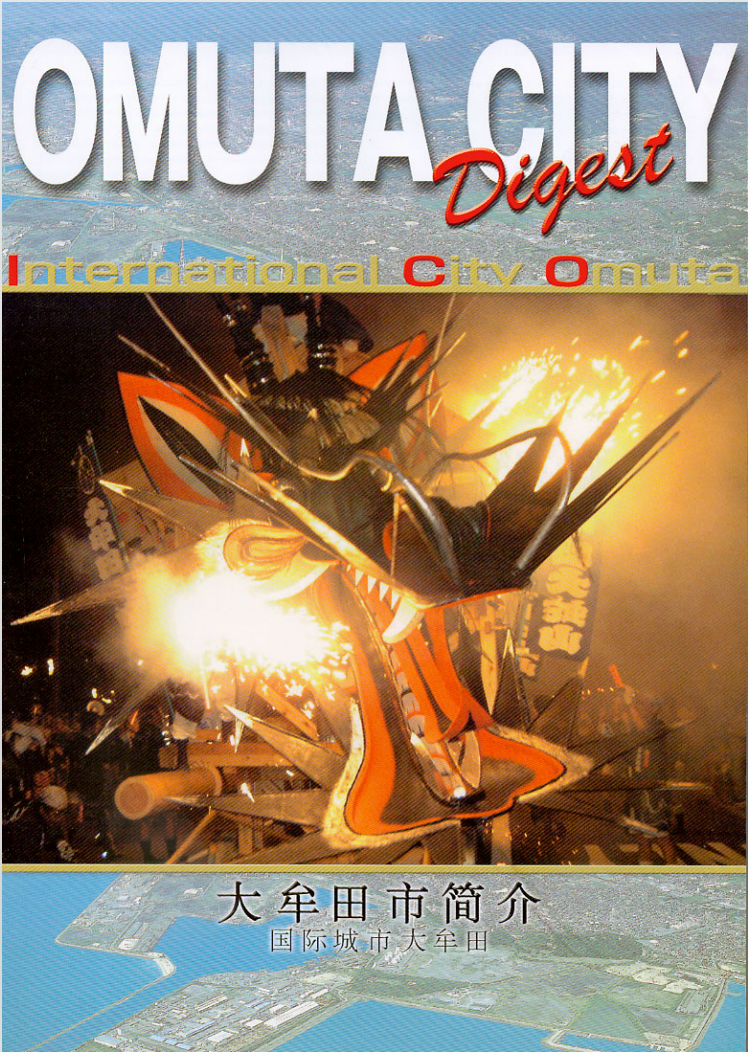
Only politicians and those trying to raise money talk  
about cure as realistic in any time span but especially  
short...

And what would “cure” look like, back to “normal”?

Age and dementia-friendly  
communities movements



# Japan -Omuta City



# Germany - Arnoldsberg



Person (with dementia and otherwise) -friendly communities are what we need

Schools are essential to community and human flourishing

Intergenerational relationship and story-based learning is the most powerful

Literacy and especially ecoliteracy is essential to human survival

# The Intergenerational School

Grew from 30 to 240 K-8 Students  
95% African American  
65% Poverty rate

Last year served 330+ adult learners

Consistently one of the top performing  
charter schools in Ohio

Internationally and nationally recognized for  
intergenerational programs and student  
success

[www.tisonline.org](http://www.tisonline.org)



# Intervention



# Qualitative results

<b>Quality of life:</b>	
<b>Main themes</b>	<b>Sub themes</b>
<b>Perceived health benefits</b>	Reduced stress and depression Youthful energy Cognitive stimulation
<b>Sense of purpose and sense of usefulness</b>	Role continuation Reminiscence Joy of teaching children
<b>Relationships</b>	Physical touch Proxy grandchildren Racial reconciliation Acceptance Reciprocity

“Concert offers different take on Alzheimer’s disease” Cleveland Plain Dealer  
Enhancing the role of art, music, and dance

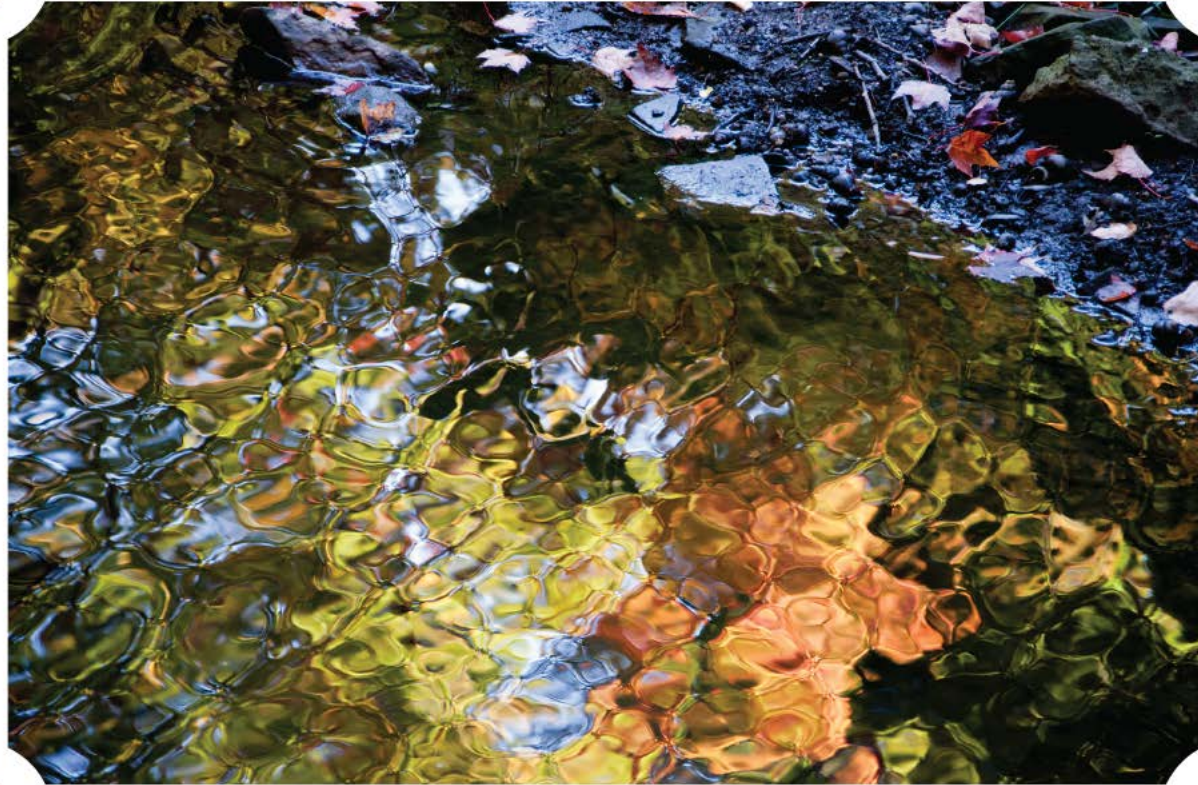


# Legacy Projects



# Freeway Fighters 1960's environmental activists





*The Legacy of Clark Freeway Fighters*



## “Occupy Nature”: Passing Activism Across Generations

In the early 1960s, a group of community activists in Cleveland calling themselves the “Freeway Fighters” began mobilizing. The target of their protest was a proposed superhighway that would tear through 200 acres of undisturbed marsh, demolish a nature center, and sully a stream called Doan Brook that meandered through several eastside neighborhoods and into the city’s cultural gardens in Rockefeller Park before emptying into Lake Erie. Championing the superhighway was a powerful and politically connected county engineer who considered the nature center and its waterways “a dinky little park” with a “two-bit duck pond” and argued the parkland was better viewed from a car than on foot.<sup>1</sup> It was the height of the post-Eisenhower freeway boom, and the building frenzy seemed an unstoppable cultural force.

But it was also the era of civil rights and antiwar movements, and protest was in the air. Galvanized by the threat to their neighborhoods, the Freeway Fighters held public forums to educate the community, organized letter-writing groups, and arranged walks through the parklands with local politicians. “Better ducks than trucks” was their unifying cry. In 1970, after the group had waged a 7-year struggle, Ohio governor James Rhodes officially scrapped the superhighway plan. Since then, more than 280,000 children have taken classes at the nature center on Doan Brook, whose oxygen-rich waters now flow into Lake Erie.

Many of the Freeway Fighters have since died, and those still living are experiencing the challenges of old age. Even so, the legacy of their activism is still embodied in the trees, waterways, and wildlife surrounding the nature center. One major beneficiary of the Freeway Fighters’ efforts has been The Intergenerational School (TIS), a Cleveland charter school located on a bluff above Doan Brook that uses the landscape as an educational resource and venue for intergenerational programming.

In March 2011, TIS students aged 12 to 14 visited a local retirement community called Judson Park—also located near Doan Brook—where nine Freeway Fighters resided. Students were charged not only with recording the stories of these activists, but also with expressing gratitude for the legacy they had left the region.

When students arrived at Judson Park, they shook hands with their elder partners and split into small groups for interviews. One Freeway Fighter, Kay Fuller, a 94-year-old woman whose memory is now challenged by mild to moderate dementia (Figure 1), energetically described to her young partners how the fight against the superhighway



Figure 1. With a picture of the nature reserve in front of her, Kay Fuller describes her role as an activist to students from The Intergenerational School.

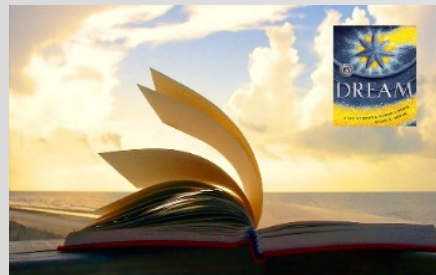
thrust her into the unexpected position of a movement leader: “I just couldn’t believe that they would put a freeway through there ..., but I never fought anything in my life. I had always been shy and afraid of my own voice, so I really had to work on it.” Then a housewife and mother of three young children, Mrs. Fuller eventually found her voice in testifying at the local city council as well as before the U.S. Congress. When students asked what practical advice Mrs. Fuller would give their generation, she paused to reflect before saying: “I think you should take the lesson that, if there is something that is worthwhile, you should be aware of it and fight for it.”

In their reflective writing after the interviews, students expressed admiration at how the Freeway Fighters had protected the local neighborhood, often assimilating the forceful language of their elder partners. As one student wrote: “There are some things that you really need to stand up and fight for when you think they’re wrong. You can’t just sit there and let people run over you, because that highway would’ve destroyed a beautiful part of this city that now is very integrated.” Another student concurred: “The freeway would’ve destroyed [our neighborhood]. It would have become neglected and empty.” Student narratives were combined with their interview

DOI: 10.1111/j.1532-5415.2012.04110.x

# Legacy Center Toronto

1 World, 1 Book



ENGAGE  
dreams / aspirations

7-Gen Resources



EXPLORE  
needs / interests

Legacy Projects

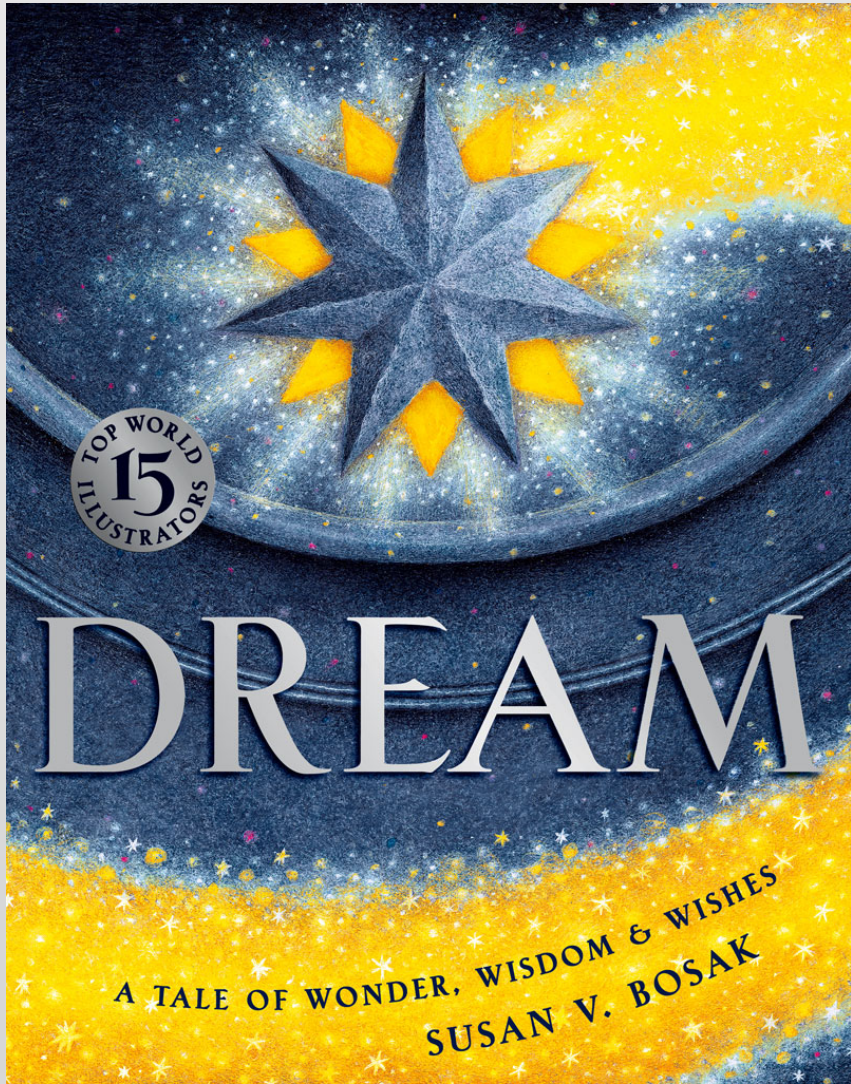


ENABLE ACTION  
assets / strengths



YOU 177 is a r/evolution in the way we think and solve problems that strategically empowers and connects youth, adults, and elders of all ages and abilities for inspired lives, stronger communities, and a sustainable world. 1 World, 7 Generations, 7 Billion People and YOU.

[www.legacyproject.org](http://www.legacyproject.org)





# World Dementia Council lead by World Dementia Envoy –what will the **legacy** of the G7 be?



## World Dementia Envoy address to ADI Conference

Dennis Gillings, World Dementia Envoy sends a message to the Alzheimer's Disease International Conference, San Juan, Puerto Rico, 2014





“Think like a mountain” – a powerful metaphor to rethink dementia

What is **aging** (in community) about?

How can **science** contribute to **life**?

How central is the **brain** to thinking and valuing?

What does it mean to be a mortal **human being**?

