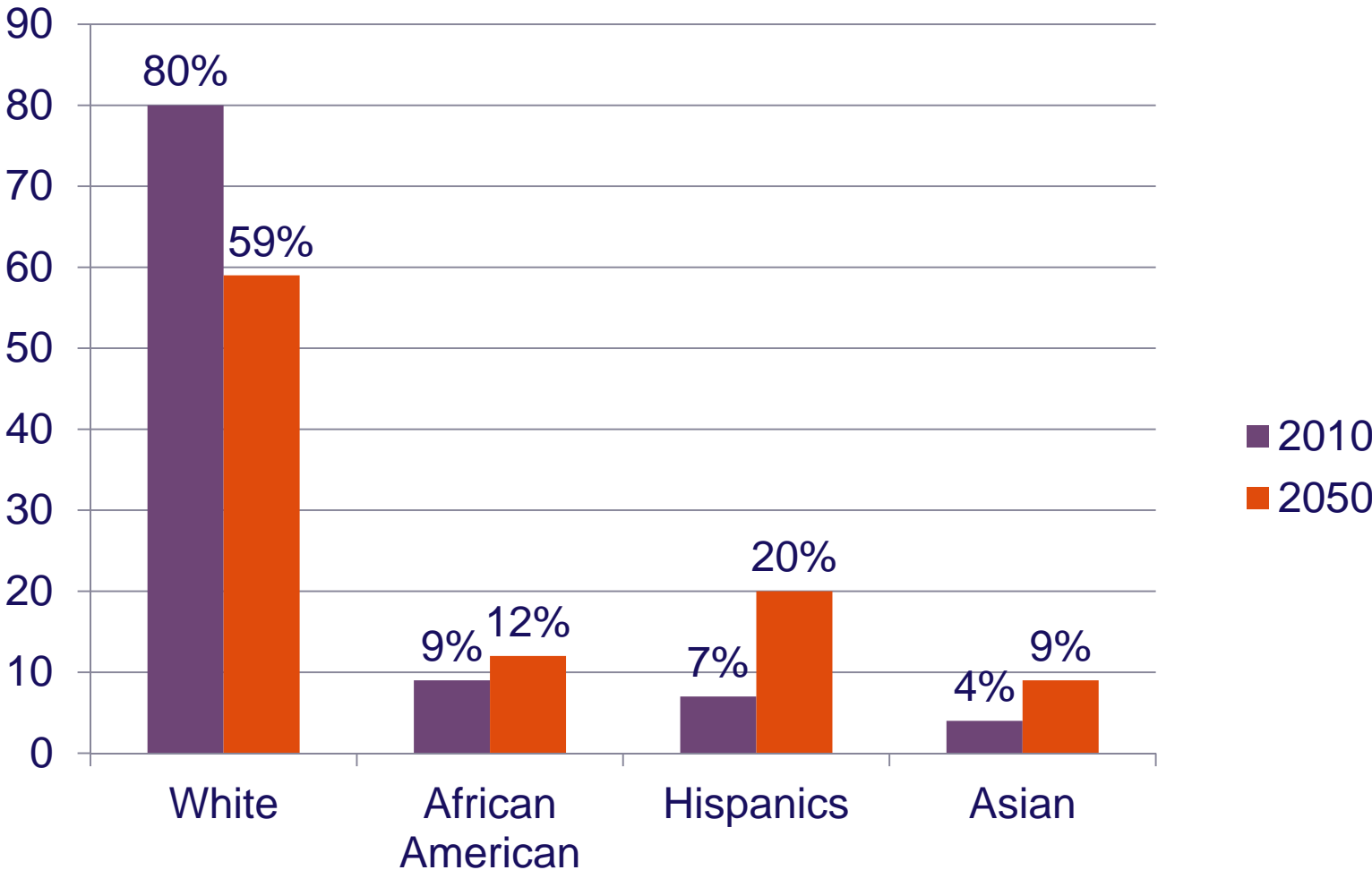


# Cultural Competency and Dementia Care

August 16, 2012

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Director, Early-Stage Initiatives

# U.S. Population Aged 65 and Older



# What We Know

- Over 5 million Americans with Alzheimer's disease
- African-Americans are almost two times more likely Alzheimer's and other dementias
- Older Hispanics are at least one and one-half times more likely to have Alzheimer's and other dementias

# Risk Factors

- High blood pressure, diabetes, heart disease and stroke
- Socioeconomic Factors
  - low level of education
  - low income
  - resided in a rural area as a child,
- No known genetic factors can account for the differences in the prevalence

Table 11: Percentage of Americans Aged 55 and Older with Selected Diseases by Race/Ethnicity and Cognitive Status, Health and Retirement Study, 2006

Race/Ethnicity and Cognitive Status	Disease				
	High Blood Pressure N=9,744	Heart Disease N=4,468	Diabetes N=3,463	Stroke N=1,361	Cancer N=2,519
<b>White</b>					
All	54	26	17	7	16
With normal cognition	52	13	16	5	15
With cognitive impairment	61	41	20	27	14
<b>African-American</b>					
All	72	24	31	11	11
With normal cognition	69	19	30	8	10
With cognitive impairment	80	36	33	25	13
<b>Hispanic</b>					
All	55	17	29	6	9
With normal cognition	52	15	26	4	7
With cognitive impairment	68	24	39	17	14

Created from data from the Health and Retirement Study, 2006.<sup>(m)</sup>

# Diagnosis

- African-Americans and Hispanics are less likely than whites to have been diagnosed with Alzheimer's or other dementia
- Long delays between first recognition of symptoms and scheduling of a medical evaluation

# Diagnostic Barriers

- Cost for evaluation
- General distrust of doctors and medical clinics
- Fear the person will lose insurance coverage
- Fear of losing his/her driver's license
- Perception that Alzheimer's is a normal part of aging

# Use and Cost of Medical Care

- Medicare-funded medical services are substantially higher for African-American and Hispanic beneficiaries aged 65 and older
- **Medicare Payments** (hospital, physician and home health services)
  - 45% higher for African-Americans
  - 37% higher for Hispanics



# Use and Cost of Medical Care

- Hospice Care
  - White Medicare beneficiaries are more likely to use hospice care than African-Americans and Hispanic beneficiaries
- Medications
  - Whites are more likely to use Alzheimer's medications than African-American and Hispanic people

# Five Elements of Becoming Culturally Competent

- Value Diversity/Awareness and Acceptance of Differences
- Self – Awareness
- Dynamics of Differences
- Knowledge of Client’s Culture
- Adaptation of Skills

# Ten Steps to Providing Culturally Sensitive Dementia Care

1. Consider each person as an individual
2. Understand the linguistic, economic and social barriers
3. Understand that families are from different cultures
4. Do not place everyone in a particular ethnic group into the same category
5. Respect cultural differences regarding physical distance and contact

# Ten Steps to Providing Culturally Sensitive Dementia Care

6. Cultivate relationships with families over time
7. Consider the family's background and experience
8. Consider the culture's typical perceptions
9. Understand the impact of a family's culture
10. Regard the faith community for various cultures as a critical support system

# Culturally Sensitive Dementia Care

## Black/African-American Culture

- Largest minority group in the U.S.
- Represent 12% of the U.S. population
- 2.7 million African-Americans age 65 and over.
- Projected to be 8.6 million by 2050

# Cultural Perspectives of Alzheimer's Disease

- “Just getting old”
- “Old-timer’s disease”
- “Normal part of aging
- Tend to downplay significance of cognitive and behavioral changes
- Did not view the changes as the result of illness

# Family and Home

- Caregivers hold strong values of responsibility toward the family and the extended family network
- Care is usually provided by extended family, including a network of friends who are considered family
- Elders are respected, obeyed and considered a source of wisdom
- Generations often live in the same home, with care provided to children and elders at the same time
- Likely to keep relative at home longer, prior to placement in nursing home- last resort
- Families may refuse services because they do not believe they need it, in spite of high levels of stress

# Barriers to Obtaining a Diagnosis

- Respect for the individual's independence, dignity and wishes for as long as possible
- Negative perception of health care provider attitudes and behavior
  - Denigrated
  - Devalued
  - Disrespected observations and concerns
  - Dismissed
- Crisis triggers need of being evaluated



# Facilitators to Obtaining a Diagnosis

- Informal networking
  - Most influential facilitator
- Clear, unambiguous communication
- Referral to/coordination of support services
- Self education

# Getting a Diagnosis

- Less likely to take relative to specialty clinic
- More likely to use neighborhood health clinics, hospital out-patient departments, emergency rooms and public clinics
- May result in fewer opportunities for referral and follow-up

# Help Seeking Methods

- Frequently seek support from their faith community, including ministers and church groups
  - Most frequently used coping strategy is prayer
- Caregivers often find solace in their religion, and use it as a means of coping with their feelings about their loved one's illness.
- Families are typically very private, not sharing concerns with strangers.

	Hispanics	Vietnamese
<b>Family and Home</b>	<ul style="list-style-type: none"> <li>- Family is center of most activity and support</li> <li>- Care provided by extended family</li> <li>- Unlikely to seek out long term care options</li> </ul>	<ul style="list-style-type: none"> <li>- Family is foundation of daily living</li> <li>- Elders are highly respected and obeyed</li> <li>- Oppose long-term care – shameful to place in residential care</li> </ul>
<b>Cultural Perspectives</b>	<ul style="list-style-type: none"> <li>- Normal part of aging</li> <li>- Punishment for past sins, bad blood or mental illness</li> <li>- Don't seek out services – brings shame to family</li> <li>- “el mal de ojo”</li> </ul>	<ul style="list-style-type: none"> <li>- Mental illness with shame attached</li> <li>- Shame extends to entire family</li> <li>- Seen as natural consequence of aging</li> </ul>
<b>Religion and Spirituality</b>	<ul style="list-style-type: none"> <li>- Most practice Catholicism, some are members of Protestant denominations</li> </ul>	<ul style="list-style-type: none"> <li>- 2/3 practice Buddhism</li> <li>- Substantial influence on beliefs and lifestyle</li> <li>- Confucianism and Taoism</li> </ul>
<b>Help Seeking Methods</b>	<ul style="list-style-type: none"> <li>- Doctors viewed as authority figures</li> <li>- May receive health care information from Spanish language media</li> <li>- Typically desire personal relationship with service providers</li> <li>- Older Hispanics often do not drive, transportation issues</li> </ul>	<ul style="list-style-type: none"> <li>- Language barriers prevent access health care information and other services</li> <li>- Family provides most of care – disregard long-term care</li> <li>- the important virtue and primary duty of respect, obedience, and care for one's parents and elderly family members.</li> </ul>

# Challenges in Outreach to People from Diverse Cultures

- Lack of culturally appropriate outreach
- Limited funding
- Failure to engage local leaders
- Failure to use peers
- Language and communication barriers
- Attitudinal barriers
- Shortage of individuals from diverse cultures in disability services professions
- Lack of information about resources
- Lack of coordinated services

# Outreach Recommendations

## Person-Centered Planning

1. Increase marketing efforts in ethnic communities
2. Use non-traditional outreach methods
3. Conduct focus groups

*Hasnain, Sotnik and Ghiloni (2003)*

# Person-Centered Planning

## Marketing Strategies

- Provide examples/stories to explain abstract concepts
- Work with community-based organizations and identify a contact person as a collaborator
- Identify a gatekeeper
- Avoid pushing American values on individualism into practice
- Encourage community ownership

# Person-Centered Planning

## Family and Cultural Influences

- Spend extra time getting to know the family
- Include extended family members and kin relationships
- Be prepared to spend time with family after the meeting
- Accept refreshments or insistent dinner invitations



# Person-Centered Planning

## Communication Strategies

- Avoid ethnic stereotyping
- Avoid rushing or giving that impression as it can lead to distancing
- Provide language and other related accommodations
- Avoid the use of jargon and service delivery terminology

# Person-Centered Planning

## Building Capacity

- Use cultural informants to assist in working with their communities
- Use the media to inform the community
- Use a community liaison to gather information and to generate possible referrals
- Use network of consumers/parents to educate and inform other families

# Characteristics of Programs with Culturally Competent Principles/Values


- Clearly defined philosophy and policies
- Staffing patterns that reflect the ethnic makeup of the population served
- Emphasis on training, education and curriculum development to address cultural issues
- Empowerment – most critical element of cultural competence

# Hispanic Outreach

**La Familia Latina y Problemas de la Memoria**  
La Enfermedad de Alzheimer

(The Latino Family and Alzheimer's Disease)

**Narradora**  
Maria Elena Salinas



alz.org/español • alzheimer's association [Regresar a la página principal](#)

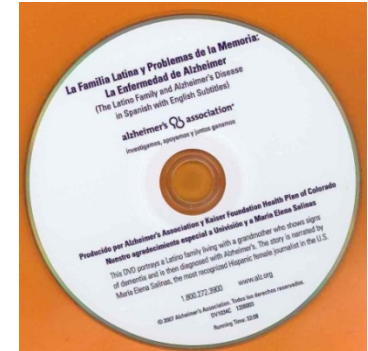
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## Latinos y Alzheimer

Y se estima que el número de Latinos que sufren de la enfermedad de Alzheimer aumentará un 600 por ciento en el año 2050. Aprender sobre la enfermedad para poder mejor cuidar no solamente de su ser querido pero también de usted mismo.

**EMPIEZA AQUI**

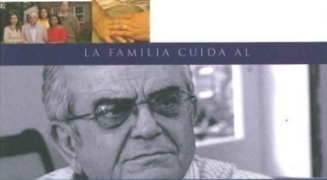



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**¿QUÉ LE PASA AL ABUELO?**

LA FAMILIA CUIDA AL ENFERMO DE ALZHEIMER

1.800.272.3900  
www.alz.org



## 10 señales de advertencia de la enfermedad de Alzheimer

Colocar cosas fuera de lugar es una de las 10 señales de advertencia de la enfermedad de Alzheimer. Reconocer los síntomas es el primer paso en hacer algo acerca de ello. [Aprenda acerca de 10 señales.](#)



### Latinos y el Alzheimer

Mientras que la ciencia apenas está descubriendo el impacto que la enfermedad tiene en los Hispánicos, lo que

Encuentre su oficina local



Código postal



[Búsqueda por estado](#)

24/7 de ayuda  
1.800.272.3900  
info@alz.org

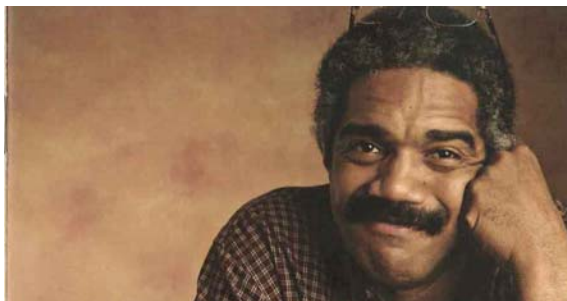
información básica sobre la enfermedad de alzheimer

¿qué es y qué puede hacer usted?



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# African-American Outreach

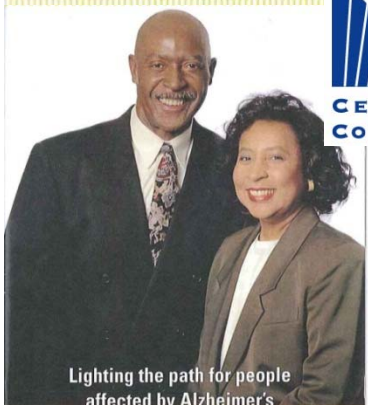


Is it Alzheimer's or just signs of aging?  
**10 signs every African-American should know**



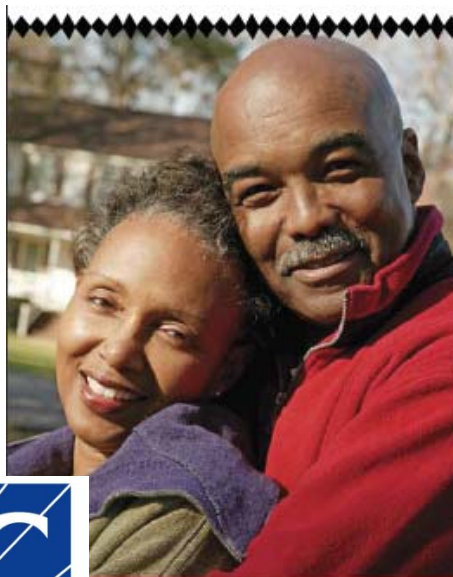
Staying strong  
 Stress relief for the African-American caregiver

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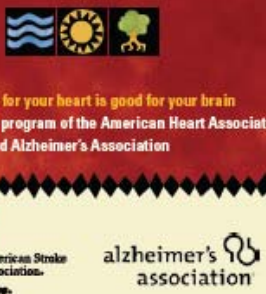


Lighting the path for people affected by Alzheimer's

African-American clergy guide  
 alzheimer's association



**strong heart and sharp mind**  
 A guide to heart and brain health for African-Americans



What's good for your heart is good for your brain  
 A public awareness program of the American Heart Association and Alzheimer's Association

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Our vision is a world without Alzheimer's  
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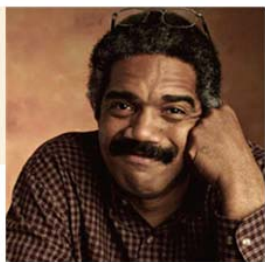
In My Community | Alzheimer's Disease | **Living with Alzheimer's** | We Can Help | Join the Cause | Professionals & Researchers

Home > Living with Alzheimer's > African-Americans

**African-Americans and Alzheimer's Disease** Text Size: A A A Print E-mail

- Introduction ▶
- 10 Warning Signs
- Brain Health
- Join the AEDA

African-Americans may be at a higher risk for Alzheimer's disease. Know the warning signs and be aware.



Attention organizations and churches:  
 Join the Alzheimer's Early Detection Alliance to raise

Many Americans dismiss the warning signs of Alzheimer's, believing that these symptoms are a part of normal aging. They are diagnosed too late and miss the opportunity to get the best care possible. This is of even greater concern for African-Americans, who are more likely to develop Alzheimer's disease than other populations.

African-Americans have a higher rate of vascular disease (diseases involving blood vessels, including heart attack and stroke) – one of the suspected risk factors of Alzheimer's disease. By working together, we hope to reduce these risk




**DUNK Alzheimer's**  
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Larry Nance  
 Alzheimer's  
 Champion

# International Diversity

## Inside the Brain: An Interactive Tour

Text Size [A](#) [A](#) [A](#) [Print](#) [E-mail](#)



The Brain Tour explains how the brain works and how Alzheimer's affects it.

[START TOUR →](#)

**Taking the tour:** There are 16 interactive slides. As you view each slide, **roll your mouse over any colored text** to highlight special features of each image. Then, click on the arrow to move to the next slide.

Take the Brain Tour in...

<a href="#">الجولة دماغك</a> (Arabic)	<a href="#">Vodič kroz Mozak</a> (Bosnian)	<a href="#">探索大腦之旅</a> (Chinese)
<a href="#">Exploration du cerveau</a> (French)	<a href="#">Gehirn-Tour</a> (German)	<a href="#">Il viaggio interattivo nel cervello</a> (Italian)
<a href="#">ブレインツアーは</a> (Japanese)	<a href="#">뇌 투어</a> (Korean)	<a href="#">Podróż w głąb mózgu</a> (Polish)
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	<a href="#">Tham quan Não</a> (Vietnamese)	

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# Questions?