



ETHICS OF ALZHEIMER'S DISEASE TESTING

Linda CW Lam
Department of Psychiatry
The Chinese University of Hong Kong



Plasma phospholipids identify antecedent memory impairment in older adults

Mark Mapstone,, Amrita K Cheema,, Massimo S Fiandaca,, Xiaogang Zhong,, Timothy R Mhyre,, Linda H MacArthur,, William J Hall,, Susan G Fisher,, Derick R Peterson,, James M Haley,, Michael D Nazar,, Steven A Rich,, Dan J Berlau,, Carrie B Peltz,, Ming T Tan,, Claudia H Kawas & & Howard J Federoff

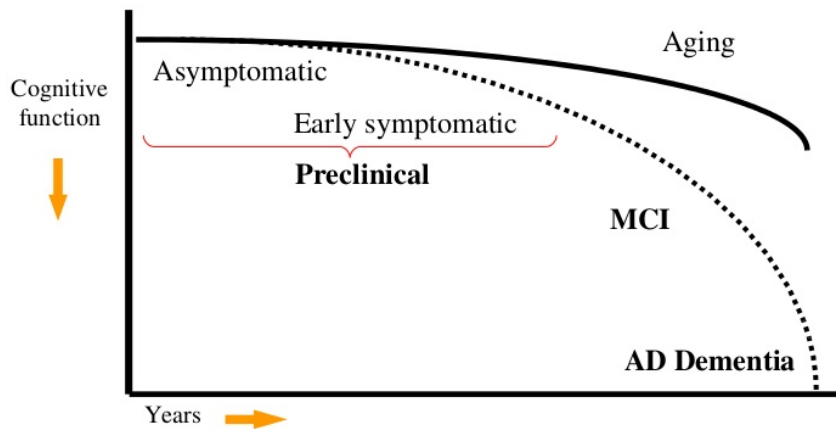
Nature Medicine 20, 415–418 (2014) doi:10.1038/nm.3466

A blood test that may predict onset of clinical Alzheimer's disease in 2 to 3 years with 90% accuracy.
Do you want it??

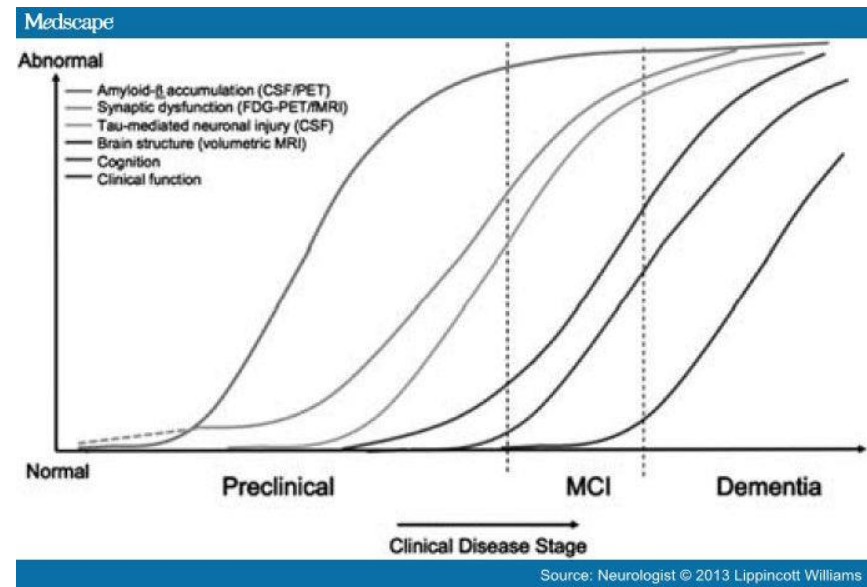
Alzheimer's disease is a complex disease with long asymptomatic preclinical phase



The continuum of Alzheimer's disease



Sperling et al *Alzheimer & Dementia* 2011
NIA-AA Preclinical Workgroup





Goals of testing

- Early disease identification
- Early disease treatment
- Better health care planning



Early disease identification

Early disease treatment

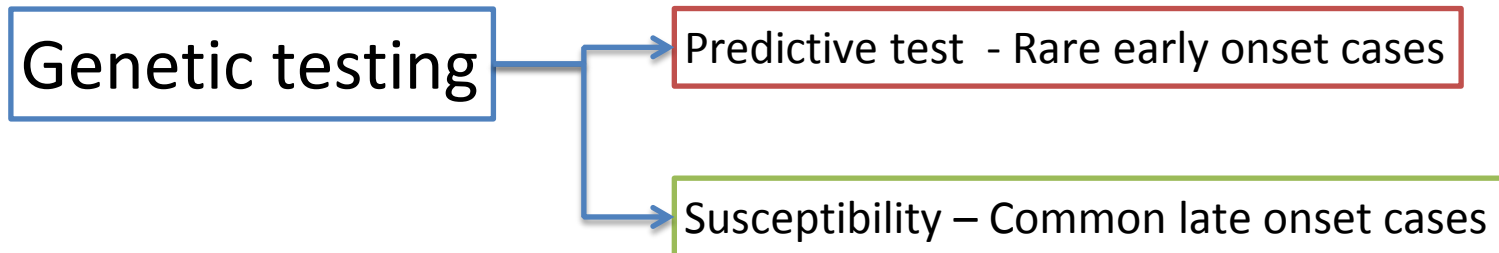
Advanced care planning

GOALS OF TESTING

Alzheimer's disease testing

- Genetic testing
 - Rare autosomal dominant inheritance
 - Susceptibility gene for common form of AD (Apo E)
- Biomarkers of neurodegeneration
 - PET scan
 - Amyloid deposition
 - CSF
 - Amyloid and Tau levels
 - MR scan
 - Hippocampal atrophy
 - Peripheral markers
 - Protein
 - Micro-RNA
 - Cognitive function

Alzheimer's disease testing



Positive test for susceptible gene increases risk of AD for 3 to 10 folds with earlier age of onset – **NOT definite for clinical disease in a lifetime**

Alzheimer disease testing



Biomarker evaluation

Predictive test – markers of neurodegeneration

- The most sensitive test may show neurodegeneration **20 years** before symptoms occur.
- The markers that show high predictive value in a few years are likely to be associated with **subtle impairments already**.
- Some test are **invasive**, some are **expensive** and **radioactive**.
- Some people with positive biomarkers are **normal** in cognition.



Why early identification?

Early disease identification

Early disease treatment

Advanced care planning

GOALS OF TESTING

Curative treatment not yet available



- Available treatment is only symptomatic with no disease modifying effects
- Some protective factors
 - Lifestyle activities
 - Physical exercise
 - Cardiovascular fitness
 - Absence of depression
- **Would testing results influence lifestyle or risk factor modification? Or**
- **Do we need a positive test result to change to a healthier lifestyle?**

Curative treatments may be available??



- Earlier knowledge with special attention to research and new treatment options
- For those with availability & resources, probably a selected group in the foreseeable optimistic future



Early disease identification

Early disease treatment

Better health care planning

GOALS OF TESTING

Better Health Care Planning



- Advanced Health Care Planning
- Financial arrangements & Enduring power of attorney
- Advanced Directives
- Insurance

The other side of the story

- Psychological reactions towards positive test results
 - Depression
 - Anxiety
 - Sensitivity to subjective cognitive problems
 - **Chronic depression is a risk factor for Alz Disease**
- Poorer objective cognitive test results in people with known positive genetic tests
- Stigmatization
- Logistic issues
 - Health Insurance
 - Mental Capacity



Considerations

- Strong Family history
- Age
- Current cognitive functional status
- Specific concerns
 - Early treatment
 - Finance planning
- Testing
 - Sensitivity and specificity
 - Predictive value and time frame
 - Cost
 - Invasiveness
 - Potential harm (radioactivity)

Considerations – Hong Kong Chinese Community



- Strong family history
- Age
- Current cognitive functional status (Early detection not widely known)
- Specific concerns
 - Early treatment (Disease modifying agents not yet available)
 - Finance planning (Limited community awareness)
- Testing
 - Sensitivity and specificity
 - Predictive value and time frame (Low prevalence of genetic susceptibility gene, Apo E, in Chinese population)
 - Cost (High cost prohibitive)
 - Invasiveness (CSF not acceptable)
 - Potential harm (radioactivity) (Relative but not absolute



THANK YOU