

A photograph of an older man with white hair, wearing a grey baseball cap, a light-colored long-sleeved shirt, and light-colored pants. He is sitting on a rocky ledge, looking off to the side. He has a large blue backpack on his back and is holding a pair of binoculars in his right hand. The background is a clear blue sky with some green foliage visible on the left.

UNIVERSITY OF KANSAS
ALZHEIMER'S PREVENTION PROGRAM
A Guide to Risk Assessment

KU
**ALZHEIMER'S
DISEASE CENTER**
The University of Kansas Medical Center

WHAT IS THE KU ALZHEIMER'S PREVENTION PROGRAM (APP)

The KU Alzheimer's Prevention Program is a comprehensive research effort to examine strategies to improve health and reduce your risk for chronic diseases, including Alzheimer's disease. If you are 65 years or older and do not have dementia or Alzheimer's disease you may be eligible. By enrolling, you will receive:



1. **Alzheimer's Risk Assessment:** This assessment includes an amyloid PET scan, which can detect changes in your brain that might indicate you are at higher risk for developing Alzheimer's disease.
2. **General Health Screen:** This includes a thorough assessment of your diet and physical function.
3. **Healthy Lifestyle Prescription:** We will provide you with an action plan targeting diet and exercise to potentially reduce your long term risk of chronic disease and potentially Alzheimer's disease.
4. **Surveillance examinations:** You will receive periodic check-ups with our medical staff to assess your memory and thinking in order to detect cognitive changes if they emerge.
5. **Study opportunities:** If you are eligible, you will be offered opportunities to enroll in medical studies focused on preventing Alzheimer's disease and enhancing healthy aging. These additional studies will always be entirely optional.

Join us and help accelerate the discovery of effective ways to delay or prevent the onset of Alzheimer's disease.

INTRODUCTION

Alzheimer's disease affects over 5 million Americans, nearly 1 in 8 people over the age of 65. We know about many risk factors for Alzheimer's disease, but older age is the strongest risk factor.

Doctors don't know yet what causes the disease. There is evidence that Alzheimer's disease is related to the accumulation of a protein called amyloid in the brain. Amyloid is normally found in our brain, but in people with Alzheimer's disease it appears to accumulate abnormally. This buildup of amyloid occurs many years, perhaps decades, before the first symptoms of memory loss become apparent.

Doctors are now able to use a new brain scanning technique, called amyloid imaging, to detect the presence of amyloid in the brain. The KU Alzheimer's Prevention Program is using this new technique to assess an individual's risk of developing Alzheimer's disease.



MANAGING RISK FACTORS FOR ALZHEIMER'S DISEASE

A growing body of scientific knowledge suggests that Alzheimer's disease shares many features in common with other preventable diseases. An estimated 3 million Alzheimer's cases worldwide could be prevented with lifestyle changes, which we know reduce the risk of chronic diseases like cardiovascular disease and diabetes. Physical inactivity is the single largest contributing factor to these diseases in the U.S. The effect of inactive lifestyles is made worse when accompanied by poor nutrition.

About KU Alzheimer's Disease Research Programs

The research programs of the KU Alzheimer's Disease Center, including the Alzheimer's Prevention Program, focus on how exercise and nutrition influence healthy and unhealthy aging.

The KU Alzheimer's Disease Center has a strong history of studies focused on lifestyle factors, including how exercise relates to brain health. For example, our scientists have found that increased physical fitness may slow the brain changes associated with Alzheimer's.



WHAT WE DO KNOW: RISK FACTORS FOR ALZHEIMER'S DISEASE

Age is the number one risk factor for Alzheimer's Disease

The prevalence of Alzheimer's disease for people in their 60's is estimated to be about 2 percent but risk rises rapidly after this with the prevalence reaching nearly 50 percent in those over the age of 85.

Other Risk Factors

In addition to age, there are a number of other Alzheimer's risk factors.

- Cardiovascular disease: Individuals with heart disease and risk factors for heart disease, such as high cholesterol, obesity, smoking and uncontrolled hypertension, appear to increase your risk for developing Alzheimer's disease.
- Diabetes: Type II diabetes is also associated with a higher risk of developing Alzheimer's disease.
- A number of other risk factors have been identified, including head injury and depression.

Protective Factors

Some factors appear to reduce one's risk of developing Alzheimer's disease.

- Education: People with a higher level of education appear to have a lower risk of developing Alzheimer's disease.
- Exercise: People who exercise routinely appear to have a lower risk of developing Alzheimer's disease.

Notably, we can change many of these risks through lifestyle interventions. As a result, we believe that the risk of AD may be modifiable too. The Alzheimer Prevention Program is thus focused on how lifestyle interventions such as diet and exercise can be used to possibly delay or prevent the onset of Alzheimer's.

WHAT ROLE DOES FAMILY HISTORY PLAY?



The best predictor of longevity is how long your parents and relatives have lived. Given how common Alzheimer's disease is in the 80's and beyond, a family history of Alzheimer's disease can in many cases simply be related to living long lives.

Those who have a parent, brother, sister, or child with Alzheimer's are more likely to develop the disease. The risk increases if more than one family member has the illness.

Scientists have identified some genetic links to the disease,

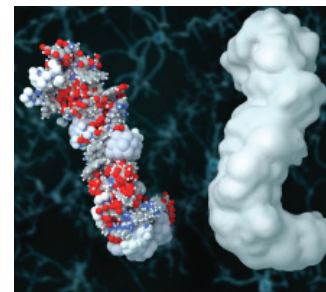
including identifying a single gene that is estimated to be a factor in 20 - 25% of Alzheimer's cases. Having the gene does not determine that you will develop Alzheimer's although your risk may be increased between 4 and 10 times compared to those who do not have the gene.

Other genes have been identified that directly cause the disease although these genes are exceedingly uncommon. When these genes are present, there is often a strong family history of early-onset Alzheimer's, often in the 40s and 50s.

UNDERSTANDING AMYLOID: IS IT THE ROOT OF THE PROBLEM?

Amyloid is a normal protein found throughout our body that, for unknown reasons, accumulates in the brain of people with Alzheimer's disease. New brain scan technology now allows doctors to measure how much amyloid is present in the living brain. Before this, the only way to measure amyloid was by examining a person's brain after they had died.

This new technology is answering many questions and creating a lot of new ones. Although most people diagnosed with Alzheimer's disease have amyloid in their brain, surprisingly, when healthy older adults without memory problems are examined with this scan, about 30 percent have evidence of amyloid deposited in brain.



Amyloid as a Risk Factor

Studies are ongoing to define more precisely what it means for healthy people to have amyloid in the brain. We do know that many people with amyloid in their brain never develop dementia, though early studies suggest a higher risk for these people. In fact, for those

who do go on to have Alzheimer's disease, amyloid is likely present for many years, perhaps decades, before the onset of memory and thinking problems.

- Currently, we have limited evidence that suggests having amyloid in the brain may be associated with slight declines in memory and thinking performance in the future.

- Doctors do not yet know what percent of individuals with amyloid in their brain will develop Alzheimer's though it is clear that not everyone with amyloid develops symptoms of the disease.
- Doctors do not know how quickly someone with amyloid in their brain might develop problems, although any increased risk is likely to play out over many years, if not decades.
- While amyloid deposited in the brain may increase the risk of Alzheimer's disease, it is clear that other factors such as your genes and lifestyle also influence whether you develop the disease. The Alzheimer's Prevention Program is designed to learn more about these protective factors to develop ways to effectively reduce your risk of developing the disease.

POSSIBLE TEST RESULTS

Brain scanning for Amyloid is a new and cutting edge technology.

The brain scan tells us how much Amyloid is present, but we do not know exactly what that amount means. There is still uncertainty about how to interpret the amount of deposited Amyloid.



What does a “positive” result mean?

- A positive result means that amyloid is likely to be present in your brain.
- A positive test does not mean you have Alzheimer’s disease.
- A positive test can be a false reading given how little is known about these measures.

Early studies suggest that the presence of amyloid may, however, increase your risk of developing Alzheimer’s disease. Scientists do not yet know what percent of people with amyloid in the brain will develop Alzheimer’s, nor do they know how quickly they might develop problems, though its likely this risk will play out over many years, if not decades.

What does a “negative” result mean?

- A negative result means that amyloid is unlikely to be present in the brain.
- A negative result does not mean that you will not develop Alzheimer’s disease.
- A negative test does not mean that you won’t later have amyloid in your brain. Early studies suggest that about 3 percent of healthy older adults will develop amyloid in their brain every year.

BENEFITS AND LIMITATIONS OF PARTICIPATING

Limitations

These tests are brand new and we do not know if they are accurate

A false positive test can mislead a patient and cause anxiety or depression.

Personal Benefits

The KU Alzheimer’s Prevention Program will work with you to assess your risks and provide a personalized plan to enhance a healthy lifestyle with exercise and a healthy diet.

We will also provide you with continued follow up evaluations (generally on an annual basis through the Alzheimer’s Disease Center) to assess for memory and thinking problems. If memory problems are discovered, we will provide you with feedback and suggestions for medical therapy.

Many patients report reduced stress and anxiety due to an improved sense of understanding and control about their health.

Benefits to Society

This study will generate new science regarding a basic mechanism of brain chemistry that may help understand Alzheimer’s disease. This study will also provide an



opportunity to study new ways to prevent Alzheimer’s disease.

What will this cost?

There will be no cost to you or your insurance because this is a research study, other than the cost of transportation to and from study visits.

If our clinicians discover something that needs medical evaluation, we may recommend you see your physician. In this case, there will be costs associated with a standard-of-care evaluation.

PRIVACY

Your privacy is of utmost concern to us. We will not release any information from this study to any outside parties or your physician, unless you specifically ask. Information from your participation in this study will remain in our research files and will not be a part of your medical record.

Federal laws (HIPAA and Genetic Information Nondiscrimination Act) and most state laws (including Kansas) prohibit discrimination regarding eligibility, benefits, or premiums based solely on medical test information. Additionally, it is KUMC policy that test results are disclosed only to health care professionals designated by the research participant, unless the participant consents otherwise.



NEXT STEPS...

Our mission is to prevent Alzheimer's disease. Join us in the fight!

Call us at (913) 588-0555 to visit with KU Alzheimer's Prevention Program health professionals to learn more about the program or to set up an initial visit.



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Promoting Healthy Brain Aging