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Protocol Level
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CLARiTI

Brain Amyloid Imaging PET Scan

Should I learn my test results?



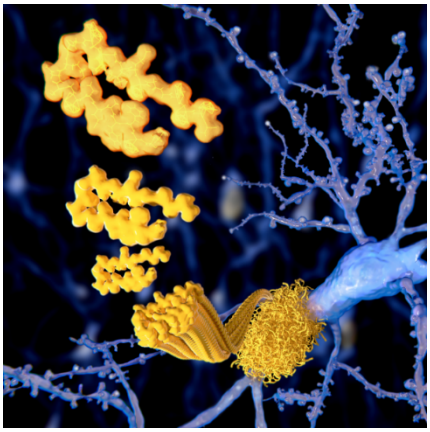
This brochure is designed to help CLARiTI participants decide whether they wish to receive the results of their brain amyloid imaging scan. Please review this brochure and, if you wish, discuss it with your loved ones or doctors. Please let our study team know if you have any questions before making your decision. You may change your mind at any time.

This brochure describes:

Developed by the CLARiTI Return of Results Core using content from the Symptomatic Subcommittee of AGREEDementia and the POINTER study (NIA R01AG062689; Alzheimer's Association U.S. POINTER-19-611541). www.AGREEDementia.org

Amyloid PET Imaging

What is amyloid?



Plaques made from amyloid protein

Amyloid is a protein normally produced in everyone's brain. Sometimes amyloid builds up into dense collections called 'plaques'. This is not normal and occurs in the brains of people who have, or will likely develop, Alzheimer's disease (AD). Amyloid builds up over many years before symptoms of memory loss begin. Some people develop plaques but never develop significant memory loss or dementia.

Until recently, amyloid could only be seen during an autopsy after a person has passed away. By using an amyloid positron emission tomography (PET) scan, we can now tell whether people have amyloid buildup in the brain before they die, and sometimes before they have symptoms.

Although a PET scan may show amyloid plaques, this does not necessarily mean a person will develop memory problems or dementia due to Alzheimer's disease.

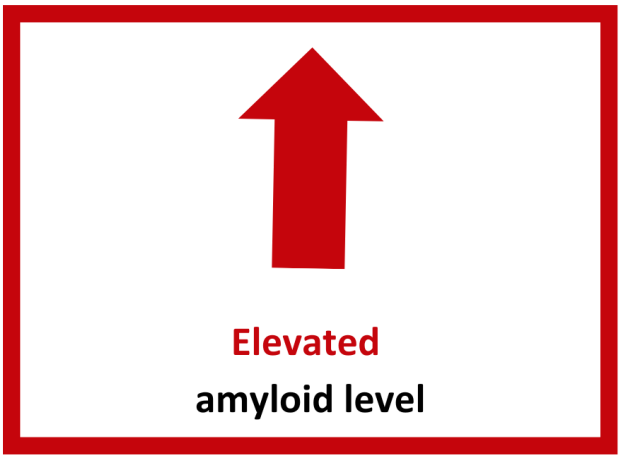
What is amyloid PET imaging?

Amyloid imaging is a special type of brain scan that detects if there is buildup of amyloid protein in the brain.

Amyloid PET imaging uses a tracer (like a dye) that briefly sticks to the amyloid plaques. The tracer is injected (like a shot) into a vein in the arm. The tracer travels to the brain and sticks to amyloid plaques, if they are present.

A special machine called a positron emission tomography (PET) scanner detects whether the tracer is sticking to the amyloid plaques. The scanner does this by detecting the small amount of radiation given off by the tracer that binds to the plaques. By looking at the PET images, doctors with special training can tell if there is significant buildup of amyloid in the brain. An "elevated" scan indicates significant amyloid buildup, and a "not elevated" scan indicates minimal or no amyloid buildup.

What are the possible results of an amyloid test?



- An elevated result means the scan detected amyloid plaques in the brain.
- An elevated amyloid test result is associated with a **higher risk** of developing memory or other thinking difficulties due to Alzheimer's disease.
- If a person has memory or thinking changes, an elevated amyloid result suggests that Alzheimer's disease is part of what is causing thinking changes. There may be other causes, like Lewy Body Disease or stroke, that are not measured by this test.

- A not elevated result means the scan did not detect amyloid plaques in the brain.
- This result is associated with a **lower risk** of developing memory or other thinking changes due to Alzheimer's disease.
- If a person has memory or thinking changes and a not elevated amyloid result, their thinking difficulties could be caused by something other than Alzheimer's disease.

Understanding Risk Relationships: Cholesterol as an Example

Cholesterol:

Having high cholesterol increases the risk of heart disease, but high cholesterol does not mean a person will necessarily have a heart attack.

Amyloid:

Having elevated amyloid increases the risk of developing memory loss, but elevated amyloid does not mean a person will definitely develop memory loss.

What information will I learn from my amyloid imaging results?

- Having elevated amyloid may **increase the risk** of memory loss or dementia due to Alzheimer's disease. Elevated amyloid does **not** mean you will definitely develop memory loss or dementia due to Alzheimer's disease.

- **'Not elevated' amyloid does not necessarily mean 'no amyloid'.** Even if your amyloid is not elevated, amyloid may still be present, just not at an elevated level.

- Amyloid imaging tests only evaluate the presence of amyloid **at the time the tests are done**. If you do not have an elevated amyloid level now, you could still develop elevated amyloid or memory loss due to Alzheimer's disease in the future.

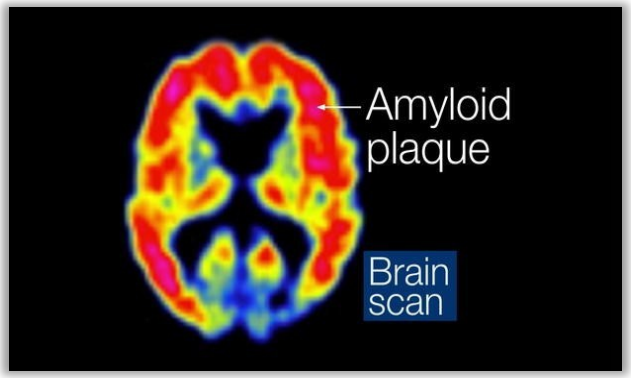
- Even if elevated, the test **cannot tell you whether you will develop memory loss or dementia** due to Alzheimer's disease. The test cannot tell you when you will develop memory loss or how severe your symptoms may be.

- If you already have memory loss, the test may help tell **whether it is caused, in part, by Alzheimer's disease**. If you have memory loss but your amyloid PET is not elevated, it may point to a different reason for your thinking changes.

- An amyloid PET brain scan **cannot tell you whether you have changes in the brain caused by other diseases, health conditions, or injuries**. It can only tell you about the type of amyloid commonly found in Alzheimer's disease.

What can I do if my scan shows an elevated amyloid level?

An amyloid scan could help determine if an anti-amyloid treatment or other medication is appropriate. It may also help you decide if you are a good fit for clinical trial research studies. You should talk to your doctor about whether these treatments and studies are right for you.



It is important to know that an elevated amyloid scan does not guarantee that these treatments will be a good fit for you. Your doctor may also want you to repeat your PET scan as not all research scans are considered valid for clinical treatment.

No matter what you might learn from your amyloid PET scan results, your brain can benefit from healthy lifestyle choices such as following a balanced diet, getting enough sleep, and participating in regular physical, mental, and social activities.

People may also use their results to make or change long-term financial and legal plans. For instance, they may choose to purchase long-term care insurance, make changes to where and with whom they live, or designate someone to assist them with decisions in the future, if needed.

Why might someone choose not to learn their amyloid imaging results?

- Some people **just don't want to know** what an amyloid scan might show. Learning their results could impact how they feel about themselves or how others treat them.

- There are potential **risks of discrimination if someone chooses to share an elevated amyloid result**. For example, someone with elevated amyloid result may share their result with their medical providers, colleagues, or employer. As a result, they may not be eligible for, or may pay more, for long-term care insurance. They may not be eligible for certain medical procedures. They may be let go from a job.

- An elevated amyloid result **does not guarantee that you are a good fit for certain treatment research studies**. Other health conditions or circumstances may make you ineligible to take part in these studies.

What to consider before deciding whether to learn amyloid imaging results…

- Will the result help you make future decisions about your healthcare or lifestyle?

- Will the result cause you extra stress or worry about the future?

- The decision to learn your amyloid result is personal. We encourage you to talk to your loved ones and to your doctor before making a decision. What you ultimately decide will be what's best for you. There is no right or wrong choice.

- Is there a family member or friend you'd like to bring to the results sharing meeting?

- Would you share your result with others in your family? With your doctors? Why or why not?

Additional Resources for More Information

Alzheimer's Disease Education and Referral Center - https://www.nia.nih.gov/about/alzheimers-and-dementia/about-adear-center
AGREEDementia - https://www.agreedementia.org
Alzheimers.gov- https://www.alzheimers.gov

NOTES

If you would like to talk to a study clinician before making a decision about receiving amyloid PET results, please notify the study team.

We would be happy to answer your questions.

Study Contact: _____

Phone Number: _____

Email: _____