AGREEDementia

# Information for Patients and Families about Anti-Amyloid Antibody Therapy

*For patients with memory and thinking difficulties due to Alzheimer's disease who may be eligible for new drug treatments*

This handout introduces the most frequently asked questions on anti-amyloid antibody therapy.

## UNDERSTANDING THE DISEASE

### 1. What is Alzheimer's disease?

Alzheimer's disease is a brain disease. While the exact cause is not known, in Alzheimer's disease, abnormal forms of proteins are built up in the brain. These abnormal forms of proteins are called amyloid plaques and tau tangles. These proteins disrupt normal brain function needed for thinking. The build-up begins many years before problems with memory and thinking start. At first, it can cause mild problems with memory and thinking, known as mild cognitive impairment (MCI), which can be detected through testing. Over time, memory and thinking problems become worse, so that people have trouble carrying out daily activities. This stage represents dementia.

### 2. What is an anti-amyloid antibody therapy?

Anti-amyloid antibody therapies remove the amyloid plaques from the brain. Over time, this may slow the progressive changes in memory and thinking due to Alzheimer's disease. This may allow people more time to participate in daily life and thus live independently.

### 3. Can the therapy cure Alzheimer's disease?

No, anti-amyloid antibody therapy is not a cure. It is intended to slow the progression of the disease, so symptoms may not worsen so quickly.

## GETTING TREATMENT

### 4. How do I take the new drug?

Anti-amyloid antibody therapies are given as intravenous (IV) infusion therapy. The IV infusion therapy is given through a vein in the arm every two or four weeks, depending on the specific drug type.

### 5. Where can I get the anti-amyloid antibody therapy?

Infusion therapy is usually given in hospitals or infusion therapy centers.

### 6. Who is eligible for anti-amyloid antibody therapy?

According to the FDA, individuals with MCI or mild-stage dementia and confirmed amyloid in the brain are eligible for treatment. This therapy is not approved for patients with more advanced stages of Alzheimer's disease or people with severely impaired functioning. It is also not approved for people with memory and thinking problems due to other conditions, such as strokes or diseases like dementia with Lewy bodies.

### 7. Do I have to take anti-amyloid antibody therapy forever?

Your healthcare provider, together with you, will determine the length of the treatment duration. Most patients receive anti-amyloid antibody therapies for at least 18 months before the treatment continuation is evaluated.

## TESTS & ELIGIBILITY

### 8. What other medical procedures are needed to determine eligibility for anti-amyloid antibody therapy?

Tests are needed to decide whether you can benefit from this therapy. Clinicians will perform many tests and interviews to diagnose potential causes for your memory and thinking problems. To make the right diagnosis, clinicians may use:

- Medical history
- Physical and neurological examination
- Memory/thinking testing
- Blood sampling, including APOE genotyping
- Brain imaging by magnetic resonance imaging (MRI) scans

To determine whether you have Alzheimer's disease, you may need either a lumbar puncture (to examine the cerebrospinal fluid (CSF)) or an amyloid positron emission tomography (PET).

Anti-amyloid antibody therapies may only be applied after a test shows that you have amyloid changes in your brain, either by CSF testing or amyloid PET.

### 9. What's the inconvenience for me?

You must be willing to come for the regular IV infusion therapy and for several other tests during treatment. Regular MRI scans of the brain need to be performed to monitor whether you develop certain side effects, like ARIA. Additionally, you need to attend regular clinical visits and bloodwork.

## ⚠ RISKS & SIDE EFFECTS

### 10. What are the side effects and risks?

Anti-amyloid antibody therapies have side effects and risks, which is why deciding to undergo the treatment needs careful evaluation and discussions with your doctor. The most common side effects are:

- Infusion-related reactions (for example, headache, fever, chills, nausea, skin redness, or itching)
- Amyloid-related imaging abnormalities (ARIA)
- Headaches
- Allergic reactions

However, anti-amyloid antibody therapies may cause more side effects. The complete range of side effects may be large, and not all can be predicted. In rare cases, death has been reported in patients treated with anti-amyloid antibody therapies.

It is important that you talk with your healthcare provider about the side effects. We recommend developing a treatment plan and discussing the benefits and risks of the therapy.

### 11. What are ARIA?

Amyloid-related imaging abnormalities (ARIA) refer to areas of swelling or small spots of bleeding (and rarely larger areas of bleeding) in the brain, due to damage in the small vessels in the brain. ARIA usually occurs without any symptoms. People may have symptoms associated with ARIA, including:

- Dizziness
- Headache
- Visual disturbances
- Seizures
- Worsened confusion

The majority of individuals with ARIA do not have symptoms at all, and no action may be needed.

In severe cases of ARIA, a healthcare provider may need to:

- Stop the anti-amyloid treatment
- Give intravenous steroids, antiseizure, or other medications
- Consider hospitalization

⚠ **Important Stroke Risk:** Even after strokes and in cases when drugs for blood thinning are given (e.g., for emergency treatment of stroke), the risk of bleeding under treatment with anti-amyloid antibody therapies must be carefully weighed, as it can lead to severe bleeding with life-threatening consequences. People who need treatment for an acute stroke need to inform the treating doctor if they are receiving anti-amyloid antibody therapies.

### 12. Who is particularly at risk of developing ARIA?

People who carry a specific gene version called APOE4 are at a higher risk of developing ARIA as well as serious complications from ARIA. Therefore, a person should have APOE testing before consideration of anti-amyloid antibody therapies, so the benefits and risks can be understood before moving forward with treatment.

### 13. When is therapy not an option?

Treatment is not possible in cases of:

- Certain chronic (ongoing) health conditions
- Severe vascular changes in the brain
- Diseases affecting memory and thinking other than Alzheimer's disease
- Uncontrolled bleeding disorders or ongoing treatment with strong blood thinners (e.g., warfarin (Coumadin), apixaban (Eliquis), dabigatran (Pradaxa), or rivaroxaban (Xarelto)). However, treatment with or Aspirin or Clopidogrel is possible.

## $ COSTS

### 14. What are the costs?

Anti-amyloid antibody therapy is covered by Medicare Part B. Once the Part B deductible is met, people with original Medicare pay the standard coinsurance of 20% of the Medicare-approved amount for the drug. However, costs may be different for people with Medicare supplemental coverage or with a Medicare Advantage plan. Cost coverage by other insurers may vary. Copayments for necessary examinations before and during the therapy may be required. There will also be copayments for the required MRIs.

## ✓ QUESTIONS TO ASK YOUR DOCTOR

What do I need to know before starting anti-amyloid therapy? Use the checklist below to prepare for your appointment.

☐ **Side effects**

☐ **Tests**

☐ **Travel to and from the hospital/infusion therapy center**

☐ **Costs**

☐ **Who should be informed in case of side effects?**

☐ **How will I know whether the therapy is helping?**

☐ **What happens if treatment is stopped?**

**Please consider what other important questions you would like to discuss with your doctor and use this space for additional topics:**

## REFERENCES


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***This handout is for informational purposes only and does not replace the advice of your healthcare provider. Please discuss any questions or concerns with your doctor before making a treatment decision.***


Produced by members of AGREEDementia.org (Symptomatic Group) to educate people living with or at risk for Alzheimer's Disease to support their shared decision-making with their healthcare professionals. Members include Ayda Rostamzadeh, Melissa Armstrong, Corey Bolton, Nate Chin, Lindsay Clark, Nicole Fowler, Douglas Galasko, Judy Heidebrink, Jennifer Lingler, and Allyson Rosen


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