

Anti-Amyloid Therapy for Dementia: Decision guide

If your doctor has told you that you have mild cognitive impairment or mild dementia due to Alzheimer's Disease, you may have questions about anti-amyloid therapy with medications such as lecanemab or donanemab. There are many things to think about before deciding to use these anti-amyloid medications. This handout can guide your discussions with your doctors and those closest to you.

What are anti-amyloid medications and why might I need them?

Anti-amyloid [AM-uh-loyd] medications are used to treat **mild cognitive impairment (MCI)** or **mild Alzheimer's Disease (AD)**.

- **MCI** is when you have problems with memory and thinking that are greater than what happens with normal aging. However, the changes are not serious enough to cause problems in your daily life.
- **AD** is a form of dementia that causes changes in the brain. These changes can cause problems with thinking, making decisions, or doing every day activities.

People who have AD have a build-up of proteins in their brain called **amyloid plaques** [plax]. These proteins make it hard for brain cells to talk to each other.

How well does it work?

Tests show that people with mild AD who took anti-amyloid medications for 18 months had fewer amyloid plaques in their brains than expected. They also had slightly better brain function than those who did not take the medicine.

It is important to remember that anti-amyloid medications may slow the progress of AD, but are not a cure. Your body's response to the medicine may be different from others. Because anti-amyloid medications are new, doctors do not know the long-term risks and benefits.

What are the side effects?

About 1 in 4 people who took anti-amyloid medications had serious side effects, such as:

- Swelling in the brain
- Bleeding in the brain
- Shrinking of the brain
- Increased confusion
- Vision changes
- Headaches
- Heart rhythm problems
- Dizziness
- Death (rare)
- Cough
- Diarrhea

Some side effects can be managed at home but others may require a hospital stay.

Who should not take anti-amyloid medications?

There are many reasons why you may not be able to take anti-amyloid medications. For example, if you:

- Take blood thinners such as warfarin (Coumadin), apixaban (Eliquis), dabigatran (Pradaxa), or rivaroxaban (Xarelto).
- Have recently had a seizure
- Have recently had a transient-ischemic attack (TIA) or stroke
- Are having chemotherapy for cancer
- Have severe depression
- Cannot have a MRI because of metal implants or other reasons. For example, you may live too far from a medical facility where you can get a MRI on short notice.

Your doctor may have other reasons why it is not a good choice for you.



What do I need to think about before taking anti-amyloid medications?

Anti-amyloid medications are not right for everyone. Talk with your doctor and those closest to you about the following:

- **Testing.** Your doctor will need to make sure the medicine is right for your disease and that you are healthy enough to take the medicine. They will look for amyloid plaques in your brain.
- **How they are given.** If the tests show it is okay for you to take an anti-amyloid medications, it will be given through an IV (vein) at an infusion center. IV infusion is a way to put medicine directly into your bloodstream instead of taking pills. Treatments may take about 1 hour and vary in frequency. Sometimes, infusions can cause reactions such as a fever, chills, or rash.
- **Side effects.** You will need to have regular checks for bleeding and swelling in the brain. When you start therapy, you will need frequent MRI imaging tests. Other side effects, like vision changes, nausea and vomiting, or headaches, could be a sign of a brain bleed and you may need urgent or more frequent MRIs.
If you have a stroke or heart attack while taking an anti-amyloid medication, it would not be safe for you to receive clot-busting medications that are typically used to treat these.
- **The costs.** Anti-amyloid medications and the required testing can be expensive. You will need to talk with your insurance provider to see what they will cover.
- **Participant registry.** If you are on Medicare, your doctor will need to give information about your treatment to a government registry. This is because anti-amyloid medications are new and they will be tracking its effectiveness.

Signs of bleeding or swelling in the brain

Because both brain bleeds and swelling are a risk when taking anti-amyloid medications, it is important to be aware of the signs and symptoms. These include:

- A sudden or new type of headache
- Weakness, tingling, or numbness in the face, arms, or legs
- Trouble speaking or understanding speech
- Confusion
- Seizures
- Feeling and being sick to your stomach
- Changes in vision or balance
- Passing out or can't keep your eyes open
- Personality changes

If you have any of these symptoms, call 911 or go to the nearest emergency room.

What other treatments are there for MCI and AD?

Other treatments that can be used for MCI and AD include:

- **Lifestyle.** Staying physically and mentally active is important for brain health.
- **Cholinesterase inhibitors** [koh-lin-ESS-ter-ayes in-HIB-eh-trz]. These medicines are taken regularly and most commonly as pills. They may help by temporarily improving memory performance. These medicines do not slow the progression of dementia.
- **Memantine** [MEH-men-teen]. This is a pill for moderate-to-severe AD. It may help with memory performance such as forgetfulness and confusion. It does not slow the progression of dementia.

These medicines also have side effects to consider.

Talk with your doctor about all possible treatments for AD and review the decision guide on the next page with those closest to you. These conversations will help you have a good sense of what options are best for you.

How do I decide?

Reasons to consider taking anti-amyloid medications:

- I have MCI or AD but am otherwise healthy.
- I have a treatment partner that can help me get to my appointments and watch for side effects while I am on the medicine.
- I can afford the costs of the tests, the medicine, and the MRIs.
- I can get to an infusion center for treatment.
- I do not have a history of brain bleeds.
- I do not have any of the risks listed above.
- I understand that this is a new medicine and that all the risks are not yet known.
- I do not mind sharing my health information with the drug registry.
- Other reasons: _____

Reasons I might not want to take anti-amyloid medications:

- I do not have an infusion center nearby.
- I do not live with someone who can watch for side effects while I take the medicine.
- I do not have a way to get to an infusion center.
- My insurance does not cover the cost of all the testing.
- I am uncomfortable with the idea of having many MRI scans.
- The costs of paying for it myself may be too much.
- I have a health history of brain bleeds.
- I have one or more of the risks listed in this handout.
- I am not sure it is the right fit for me.
- I do not want to share my medical information with the drug registry.
- Other reasons: _____

What do I need to do if I decide to take anti-amyloid medications?

If you and your doctor decide that anti-amyloid medications are a good option, you will need to:

- Carry a wallet card to give to all your doctors or emergency care team. You may also program the information into your smart phone to share when you go for treatment.
- Agree to take the medicine as directed and report any problems to your care team.
- Go to all follow up appointments and infusions, and get all needed MRI scans.
- Tell my doctor right away if I have any changes in my health.

Questions for my doctor
