

# A Decision Aid for Choosing if You Want to Take Anti-Amyloid Therapy



Anti-Amyloid therapy is a possible treatment option for patients with signs of Alzheimer’s disease.

Many people have found it helpful to think about the benefits, harms, and possible burdens of different treatment options for various medical conditions to decide what is right for them. This can include considering treatment with anti-amyloid therapy for Alzheimer’s disease.

This guide focuses on working through the complex decision about whether to take anti-amyloid therapy. Since there are two FDA-approved anti-amyloid therapies called **lecanemab** and **donanemab**, this tool also addresses some of the differences between the two drugs.

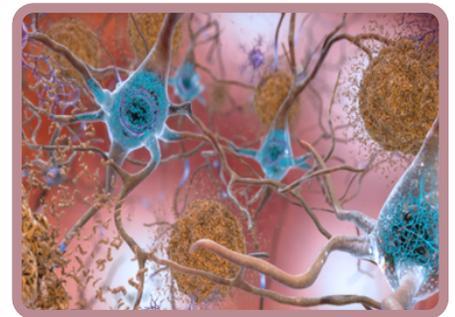
**We hope this guide will help you decide if anti-amyloid therapy is a good treatment option for you based on your goals and preferences.**

# What is anti-amyloid therapy, and how does it work?

Before learning about anti-amyloid therapy, it is helpful to have a background on **Alzheimer's disease**. Alzheimer's disease is the most common cause of a progressive change in cognition. Alzheimer's disease occurs on a spectrum, such that someone can be diagnosed with **mild cognitive impairment** or **dementia** due to Alzheimer's disease. Cognitive changes happen when nerve cells in the brain die due to Alzheimer's disease. There is currently no cure for Alzheimer's disease, and symptoms are expected to get worse over time.

Researchers are still trying to figure out why some people get Alzheimer's disease, and others do not. One thing we do know is that people with Alzheimer's disease get a buildup of two proteins in their brains:

1. **Amyloid** is one of the proteins seen in Alzheimer's disease. Toxic forms of amyloid clump together to create **plaques**.
2. **Tau** is another type of protein seen in Alzheimer's disease that clumps together to create **tangles**.



Both **amyloid** and **tau** likely have normal functions in the brain, however in Alzheimer's disease, the number of **plaques** and **tangles** increase.

**Anti-amyloid therapy** only directly targets amyloid in the brain.

**Lecanemab** and **donanemab** are two FDA-approved anti-amyloid therapies. Currently, it is only given to people with mild cognitive impairment or mild dementia due to Alzheimer's disease.

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Words in **orange** are explained in the glossary on page 8.

# Can I take anti-amyloid therapy?



## Diagnosis

You must have a diagnosis of Alzheimer’s disease causing either a) mild cognitive impairment or b) mild dementia.

## Additional Checks

Your doctors will need to order tests to see if you can take anti-amyloid therapy. They will check to make sure you do not take other medicines or have other conditions that would not be safe with anti-amyloid therapy. Different treatment centers may have different requirements for what tests are needed.

Here are some of the tests your doctors might order:

Test	What it does	What it looks for
MRI	Takes pictures of your brain	Brain bleeding
Amyloid PET Scan	Takes pictures of your brain	Amyloid plaques in the brain
Spinal Tap (Lumbar Puncture)	Takes a sample of fluid that surrounds the spinal cord and brain by inserting a needle in the low part of the back	Amyloid plaques and tau tangles in the brain; can rule out some other causes of cognitive changes
Alzheimer’s specific blood tests	Tests blood for Alzheimer’s proteins	Can be used as a screening test, but often requires confirmation with other tests.
APOE Genetic Test	Tests blood for specific genes	Genetic risk for brain bleeding and swelling
Other blood tests	Tests blood for bleeding risk and other medical issues	Looks for ability to make blood clots and other medical causes of cognitive changes

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# Does anti-amyloid therapy reduce the amount of amyloid in the brain?

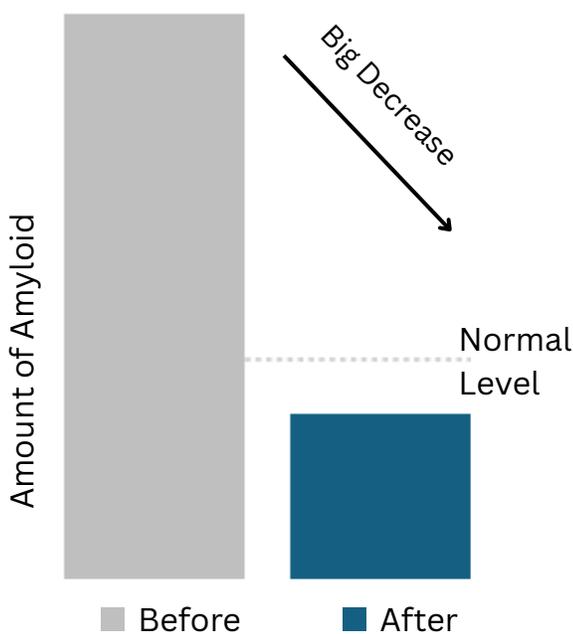
Yes!

We know that anti-amyloid therapy lowers the amount of amyloid in the brain.

## With Anti-Amyloid Therapy

Amyloid levels in the brain will go down

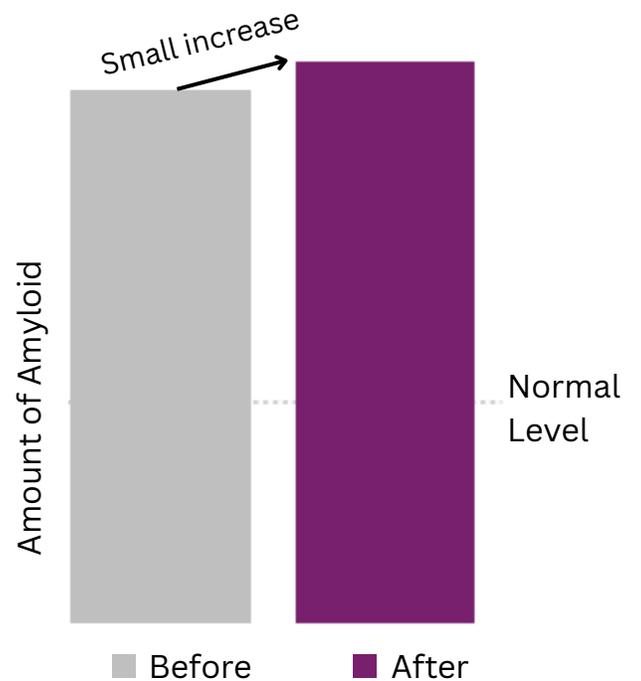
Amyloid levels after taking anti-amyloid therapy treatment for 18 months



## No Anti-Amyloid Therapy

Amyloid levels will stay the same or increase

Amyloid levels after NOT taking anti-amyloid therapy treatment for 18 months



Anti-amyloid therapy may not work the same for everyone. Age, biologic sex, **APOE genetic status**, and other factors can influence how well it works to reduce amyloid in the brain.

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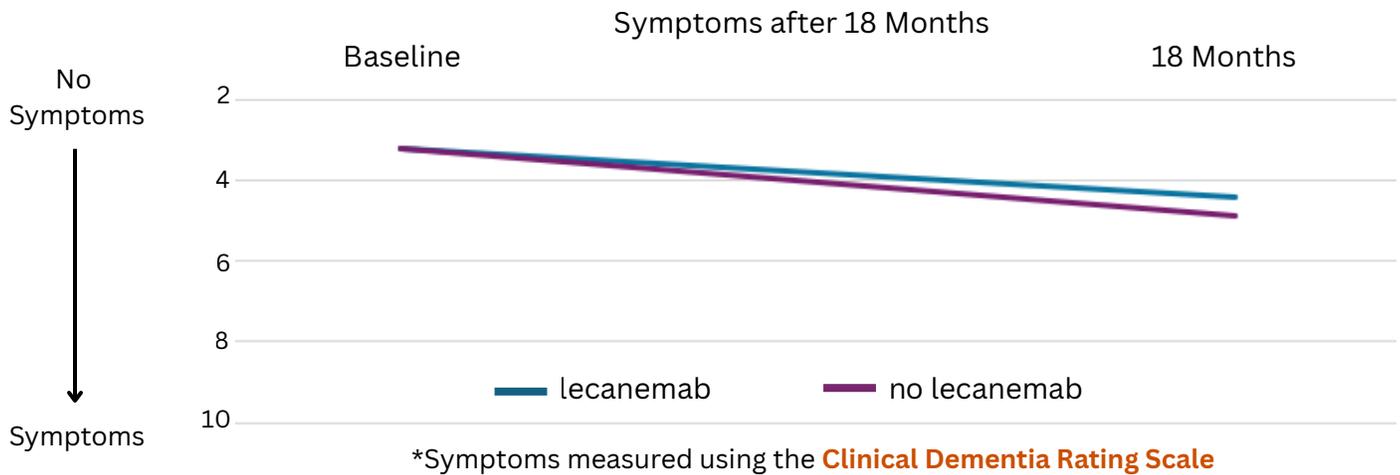
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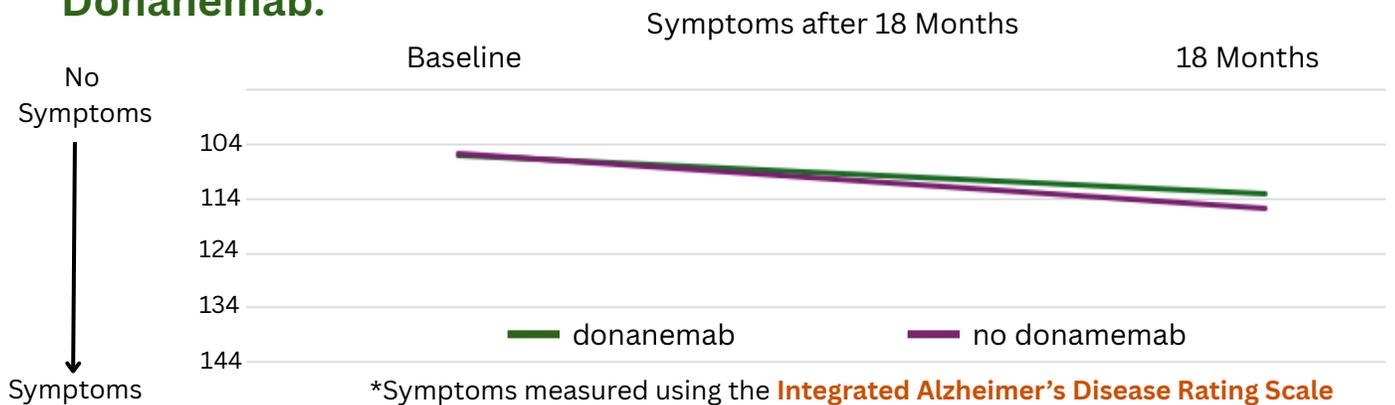
# Does anti-amyloid therapy improve symptoms?

Yes and no. Current research shows that the cognitive symptoms of Alzheimer’s disease generally do not get better. But anti-amyloid therapy slows the progression of Alzheimer’s disease on average.

## Lecanemab:



## Donanemab:



### Take Home Point:

The current research shows that anti-amyloid therapy slows the progression of Alzheimer’s disease, but symptoms still get worse over time.

Note: the two studies have different scoring because they used different tests that both measured similar symptoms.

### Notes:

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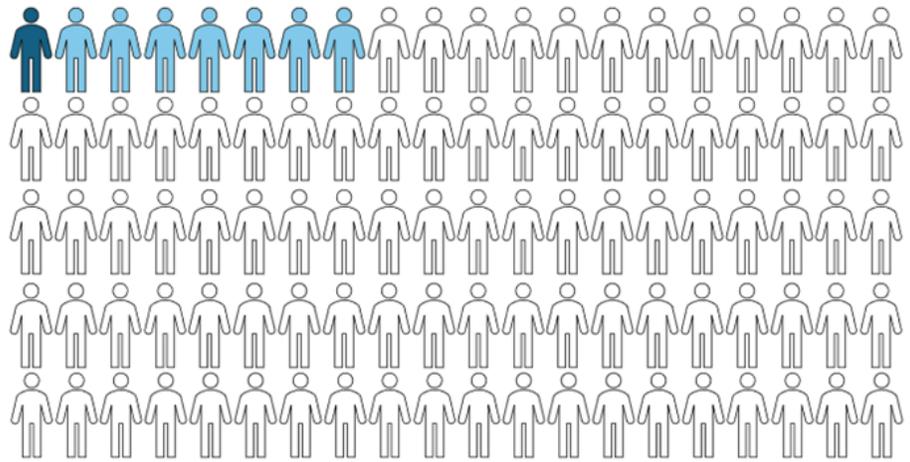
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# What are the possible risks of anti-amyloid therapy?

One potential risk is **brain bleeding**, also known as ARIA-H (Amyloid Related Imaging Abnormality – Hemorrhage) due to the anti-amyloid therapy. Most patients do not notice symptoms. Symptoms of brain bleeding can include headache, dizziness, or any new or worsening neurological symptom. During anti-amyloid therapy, you need regular MRIs to look for brain bleeding. Sometimes bleeding is severe enough that you may need to take a pause or completely stop the treatment.

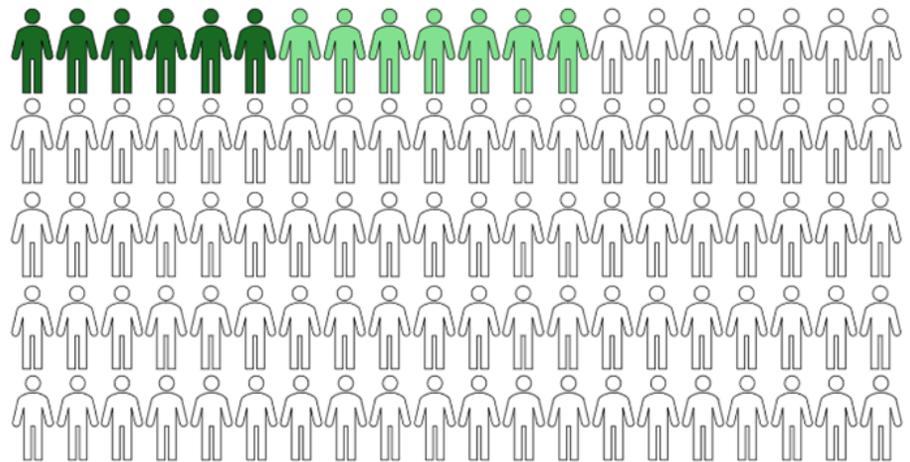
## Lecanemab

8 out of 100 people will have brain bleeding due to the drug. About 1 person will have symptoms.



## Donanemab

15 out of 100 people will have brain bleeding due to the drug. About 6 people will have symptoms.



 Has Symptoms     No Symptoms     Counts as 1 in 100

Notes:

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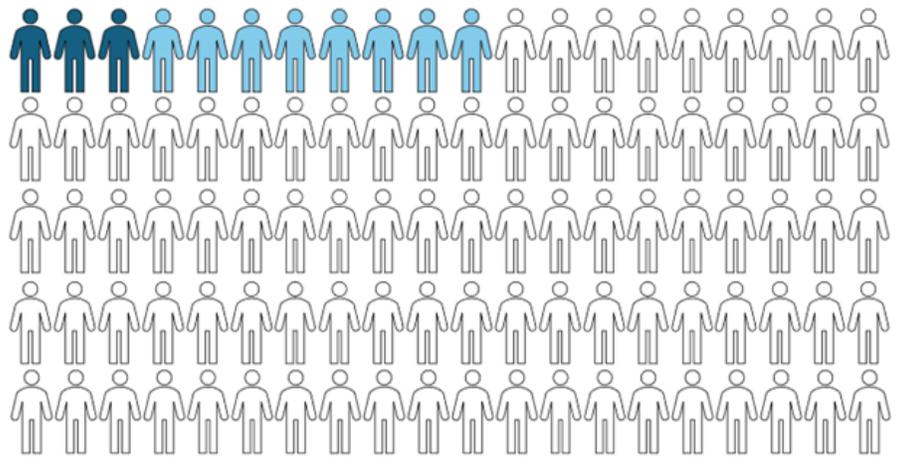
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# What are the possible risks of anti-amyloid therapy?

Another potential risk is **brain swelling**, also known as ARIA-E (Amyloid Related Imaging Abnormality – Edema) due to the anti-amyloid therapy. Most patients do not notice symptoms. Symptoms of brain swelling can include headache, dizziness, or any new or worsening neurological symptom. During anti-amyloid therapy, you need regular MRIs to look for brain swelling. Sometimes swelling is severe enough that you may need to take a pause or completely stop the treatment.

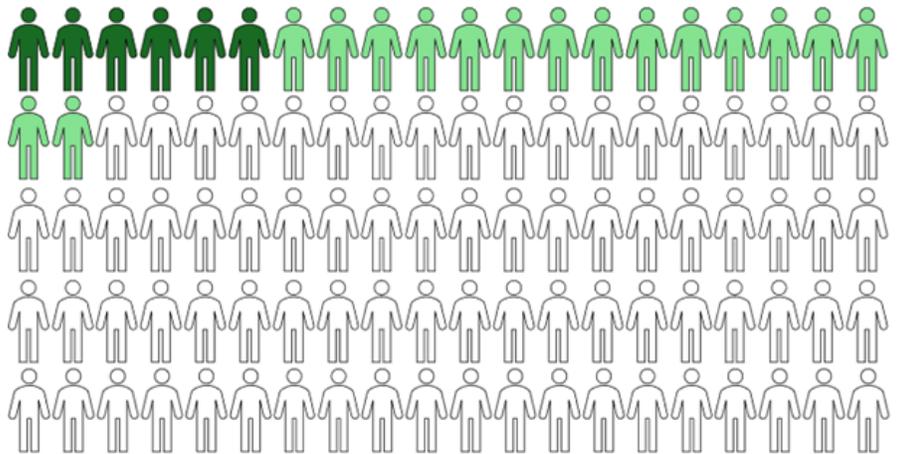
## Lecanemab

11 out of 100 people will have brain swelling due to the drug.  
About 3 people will have symptoms.



## Donanemab

22 out of 100 people will have brain swelling due to the drug.  
About 6 people will have symptoms.



 Has Symptoms     No Symptoms     Counts as 1 in 100

Notes:

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# What are other considerations for anti-amyloid therapy?

## Infusion Schedule

Anti-amyloid therapy is given through an **IV** at an infusion center. Your actual appointment duration will vary. It takes time to get the infusion prepped and you will need to be monitored after the first few infusions to check for any infusion-related reaction. You will also need a caregiver to be with you 24 hours after the first few infusions to monitor you. Infusion appointment times may decrease after the first few visits.

## Frequent MRIs

You will need MRIs at different points during treatment, as shown in the calendar below. Some people will need additional MRIs depending on the results.

### Lecanemab

The infusion happens every 2 weeks.  
The infusion takes about 1 hour.

Month 1   	Month 2   	Month 3   	Month 4  	Month 5  	Month 6  
Month 7   	Month 8  	Month 9  	Month 10  	Month 11  	Month 12  
Month 13   	Month 14  	Month 15  	Month 16  	Month 17  	Month 18  

### Donanemab

The infusion happens every 4 weeks.  
The infusion takes about 30 minutes.

Month 1  	Month 2  	Month 3  	Month 4  	Month 5 	Month 6 
Month 7  	Month 8 	Month 9 	Month 10 	Month 11 	Month 12 
Month 13 	Month 14 	Month 15 	Month 16 	Month 17 	Month 18 



# What are other considerations for anti-amyloid therapy?

## Side Effects

All drugs have side effects. Of people who use anti-amyloid therapy, up to 25% might experience infusion-related symptoms. Most reactions are mild and occur after the first few infusions. Reactions typically resolve within 24 hours and can be treated at home with over-the-counter medication. While less common, some people may have severe allergic reactions called anaphylaxis and need immediate medical attention.

## Vacation and Travel

You will need to go regularly to the treatment center and access medical care quickly. Many clinicians recommend some travel restrictions. Talk to your clinicians about any restrictions that they might have.

## Cost

The anti-amyloid medications can cost between \$26,500 and \$32,000 a year, but this does not include the costs associated with the infusions or the follow up testing. Your healthcare insurance may help cover some of these costs. For example, Medicare will cover 80% of the cost of anti-amyloid medication after your deductible is met. This means you will have to pay the other 20% out-of-pocket in addition to your deductible each year. Some people have supplemental insurance that covers the remaining amount. This cost also does not include additional costs of regular MRIs, amyloid PET scans if needed, other lab tests, and office visits. **It is important to contact your healthcare insurance directly to determine how much of your treatment costs will be covered.**

## Infusion-Related Symptoms

Generally mild:

- Fever and/or chills
- Flu-like symptoms: aches, feeling shaky, and muscle/joint pain
- New headache and/or vision changes
- Elevated or low blood pressure
- Changes in heart rate
- Feeling dizzy, light-headed or episodes of passing out
- Abdominal discomfort, nausea and/or vomiting
- Rash or other skin changes

Very rare:

- Anaphylaxis

Notes:

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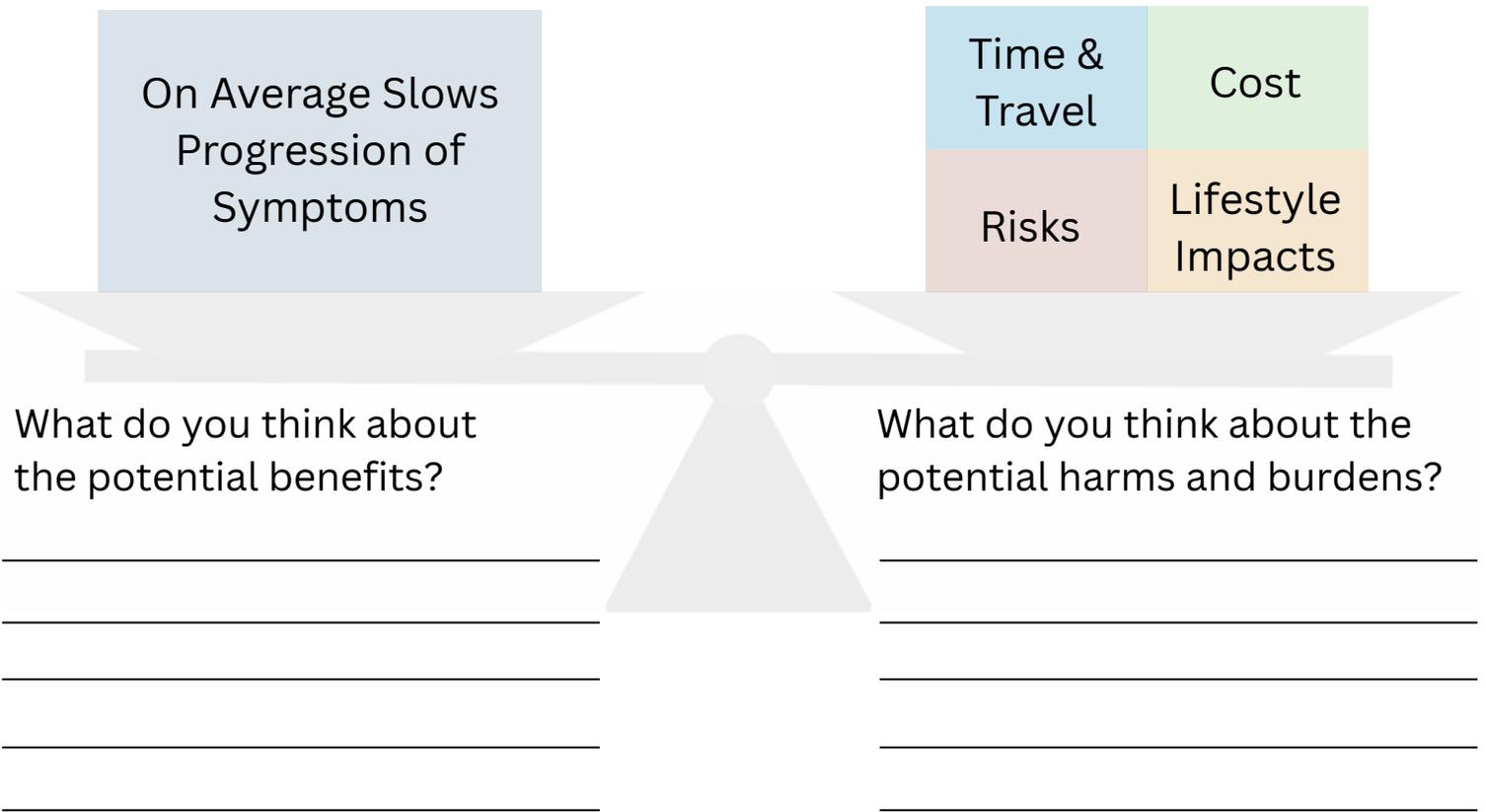
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# What is the right choice for me?

As you have been looking at this guide, you might have written down some thoughts that could help you to answer the question: Does the potential benefit outweigh the potential harms and burdens?

Imagine a scale like the one pictured below. The reasons to take anti-amyloid therapy are on one side and the reasons not to take anti-amyloid therapy are on the other. What are the most important things to you?

Feel free to use the space below to write down some thoughts:



What feels most important to you?

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# What is the right choice for me?

Figuring out the option that is best for you and your caregiver can be challenging. Take some time to think about what decision is right for you. Remember, you do not have to make this decision alone. It can help to discuss with loved ones and healthcare professionals.

## If you know which choice is best for you:

### Step 1:

- I do not want anti-amyloid therapy
- I do want anti-amyloid therapy



### Step 2: If you do want to take anti-amyloid therapy...

Which anti-amyloid therapy is right for you?

- lecanemab
- donanemab
- unsure

### Still not sure?

It is ok not to have all the answers right now. Use the space below to write down a few questions or concerns to talk about with your doctor.

My questions and concerns are:

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Remember, the choice is **YOURS** to make.

# Glossary

**Alzheimer's disease** - a progressive and irreversible brain condition that causes cognitive decline

**Amyloid** - a protein that can become sticky and toxic and forms plaques in the setting of Alzheimer's disease

**Anti-amyloid therapy** - a type of treatment that removes amyloid plaques from the brain

**APOE Genetic Status** – A gene that influences the risk for Alzheimer's disease

**Brain bleeding/ARIA-H** - Amyloid-Related Imaging Abnormality - Hemorrhage (ARIA-H) is where blood accumulates in or around the brain

**Brain swelling/ARIA-E** - Amyloid-Related Imaging Abnormality – Edema/Effusion (ARIA-E) is the abnormal accumulation of fluid in or around the brain

**Clinical Dementia Rating Scale** - An assessment tool that evaluates the severity of cognitive impairment by rating cognitive and functional decline across six domains: memory, orientation, judgment & problem solving, community affairs, home & hobbies, and personal care

**Donanemab** - a monoclonal antibody known as anti-amyloid therapy used for the treatment of Alzheimer's disease

**Integrated Alzheimer's Disease Rating Scale** – an assessment tool that evaluates Alzheimer's disease clinical trials to provide a single measure of overall disease severity by combining a cognitive testing and activities of daily living assessments

**IV** - A needle is placed in your arm/hand allowing for a liquid drug to run directly into your vein

**Lecanemab** – a monoclonal antibody known as anti-amyloid therapy used for the treatment of Alzheimer's disease

**Mild Cognitive Impairment** - a condition characterized by a measurable decline in cognitive abilities, such as memory, attention, and reasoning

**Plaques** - amyloid protein deposits that accumulate in the spaces outside nerve cells (neurons) in the brain in Alzheimer's disease

**Spinal Tap (Lumbar Puncture)** - a medical procedure that involves collecting fluid that bathes the spinal cord and brain by introducing a small needle at the low part of the back

**Tau** - a protein that can become sticky and toxic forming tangles in the setting of Alzheimer's disease

**Tangles** - tau protein deposits that accumulate inside brain cells (neurons) during neurodegenerative diseases like Alzheimer's disease

# Frequently Asked Questions

## **What happens if I stop taking anti-amyloid therapy?**

You can decide to stop taking anti-amyloid therapy at any time during the therapy process.

## **Is there anything else I can do?**

Choosing not to take anti-amyloid does not mean you are not treating your Alzheimer's disease. While it will not slow the progression of Alzheimer's disease, other medications might help with day-to-day symptoms. There are also lifestyle and healthy brain habits that may be beneficial. Ask your doctor about other support and options for your care.

## **What happens after 18 months?**

Anti-amyloid therapy research is ongoing regarding the amount of time someone might benefit from the therapy. Talk to your clinician to discuss next steps.

## **How will anti-amyloid therapy impact my symptoms in the future?**

The clinical trials ended not that long ago, so we are still learning what the long-term impacts of anti-amyloid therapy are. We will learn more as research continues.

**This information is not intended to replace  
the advice of a health care provider**







Colorado Program for  
Patient Centered Decisions



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